

[House Hearing, 105 Congress]
[From the U.S. Government Printing Office]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION, AND RELATED AGENCIES
APPROPRIATIONS FOR 1999

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HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

HOUSE OF REPRESENTATIVES

ONE HUNDRED FIFTH CONGRESS

SECOND SESSION

SUBCOMMITTEE ON THE DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION, AND RELATED AGENCIES

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PART 7B
(Pages 1373-2898)

TESTIMONY OF MEMBERS OF CONGRESS AND OTHER

INTERESTED INDIVIDUALS AND ORGANIZATIONS

Printed for the use of the Committee on Appropriations

U.S. GOVERNMENT PRINTING OFFICE
48-995 O WASHINGTON : 1998

For sale by the U.S. Government Printing Office
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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED
AGENCIES APPROPRIATIONS FOR 1999

Wednesday, February 4, 1998.

TESTIMONY OF MEMBERS OF CONGRESS AND OTHER INTERESTED INDIVIDUALS AND
ORGANIZATIONS

WITNESSES

HUGH DOWNS, ABC 20/20

DR. MICHAEL EHRLICH, M.D., AMERICAN ACADEMY OF ORTHOPAEDIC SURGEONS

Mr. Porter. The subcommittee will come to order.

This is our seventh session of public witnesses, and we have heard approximately 120 witnesses over the last three days of hearings. We will have hearings this morning, this afternoon, and tomorrow, with additional public witnesses.

Let me say that we have done our very best to accommodate as many witnesses as we possibly can. We realize that there are more who would like to testify, and we do our very best to include as many as possible and to give everyone a chance.

We would admonish witnesses that because we have so many in each panel, we would ask that you keep your remarks to five minutes. Witnesses have been very good at doing that. The staff is a little tough because they've obtained a timing device, which you will hear, to remind you when the time is up. At some point in the morning I will probably give my ``sermonettes number one and two'' about the budget process, which some of you have heard many times over now, but let me thank each one of you for coming to testify. It helps us a great deal, and I can tell you that as far as the Chair is concerned, I learn a great deal from our public witnesses.

We have scheduled you early because this is a time when

votes do not interrupt us, or are less likely to interrupt us. As a matter of fact, up to this point we have not been interrupted at all, and that allows us to hear everyone on our panel without having to run to the floor and cast votes, where we lose a great deal of time. I hope that that happens today; it may not, because there are matters being debated on the floor this morning, and we probably will have recorded votes at some point during the day.

With all that said, our first witness is Hugh Downs of ABC's 20/20, testifying on behalf of the American Academy of Orthopaedic Surgeons.

Hugh, it's nice to see you. Please make yourself at home.

Let me say that it is, in my judgment, extremely important that people who are well-known to the American people stand up for the things that they believe in and make them known to the public. It captures the public imagination, and we very much appreciate your coming here and spending your valuable time to inform us of your concerns regarding orthopaedic matters and the orthopaedic surgeons. Thank you very much.

Mr. Downs. Thank you, Mr. Chairman and members of the subcommittee. I am Hugh Downs, anchor of ABC News' 20/20. I am accompanied by Dr. Michael Ehrlich, who is Chairman of the Committee on Research of the American Academy of Orthopaedic Surgeons, and he is available to answer any medical questions that you might have afterwards.

He also has a prepared statement that will be submitted for inclusion in the record.

It is a real honor for me to speak before this subcommittee in support of the research being conducted at the National Institute of Arthritis and Musculoskeletal and Skin Diseases. This Institute supports basic and clinical research on many of the most debilitating diseases affecting the Nation's health. Your past investments are paying off, and a continued investment in biomedical research will offer the potential for individuals to resume a productive, functional, pain-free lifestyle which is so important to all of us, of which I am a prime example.

Two years and six days ago, I had bilateral knee replacement at Massachusetts General in Boston. The deterioration over a 15-year period had reached a point where if I walked seven or eight city blocks, I was ready to sit on a curb and wait for a cab because the pain was too overwhelming. It's a source of shame that I don't have a Heismann Trophy to show for ruined knees, but the fact is it was a series of dumb accidents that caused me to fetch up lame. An automobile accident in 1948 stove in my right knee. In 1966, an off-field landing--if you could call it that--in a light plane jammed both knees to the point of mild injury. During an off-trail caper in 1971 in the Tonto National Forest in Arizona, my horse and I parted company and I landed, left knee first, on a stump.

These injuries all appeared to heal, and I had trouble at that time--and up to that time--believing that there was such a thing as a permanent injury. My philosophy was that you got hurt, and then you got well.

Well, I learned that this was not true after the final folly in the saga of my knee joints. In 1981, I ran down 34 flights of stairs in a foot race with my grandson, who at that

time was 10 years old. Before I got to the bottom, I knew that I had done something very bad to my right knee. In the ensuing weeks, favoring that knee threw enough strain on the left one to harm it, and recovery was not in the cards.

Disappearance of the cartilage, with subsequent bone erosion and traumatic arthritis, got a foothold and began to whittle away at my quality of life. Over the years I adjusted and accommodated, and being a denier of some skill, I convinced myself that the feelings produced by that sorry state of my legs were annoyance and not pain, and that was okay, up to a point.

On getting medical advice about whether and when to consider total joint replacement, the answer that orthopedists always gave was, ``You'll know when.'' Well, they were right, and I knew when in the early months of 1995. The date was set for January 27, 1996, to get total joint replacement in both knees.

From what I knew of the technology and the current skills of orthopaedic surgeons, I expected a lot from this operation, and I got more than I expected. First of all, it was possible to avoid general anaesthesia. I was able to watch the entire procedure, which was an extremely educational experience.

I was able to be back in the studio and anchoring 20/20 13 days after the operation, getting around on crutches. As a result of the physical therapy and continuing regimen, I recovered muscles that had atrophied over the years, notably quadriceps, and the pain, of course, disappeared almost instantly. I am amused when people ask me now whether weather changes affect my knees and if I can feel it. I have to remind them that there are no nerves in an artificial joint, and this is a real silver lining.

After 10 months I found I could run upstairs again. That's something I hadn't done for 12 years. All this was possible because of research. Knees, I am told, are very tricky. The first hip replacement was done in 1914, but the first total knee replacement was 1968, and the rapid progress in the techniques and materials that followed are really impressive. This would not have been possible without the kind of research that produces breakthroughs and improves every aspect of such a procedure.

However, I find it curious--somebody told me recently that 60 percent of the total joint replacements are performed on women. I think this may be an area that may need to be pursued. I'm not sure I know why that is.

I am, obviously, an enthusiastic booster of orthopaedic work, having had successful surgery on the lower spine. It was a fusion in the lumbar region, L4-5, in 1965. In my neck, I had a cervical procedure, C5-6, a bone spur removal, in 1968, in addition to the knee replacements two years ago.

My bionic constitution, with two and a half pounds of cobalt chromium in my knees, sets off airport security machines more or less automatically. That inconvenience is an easy trade for the agony that I used to have, limping through those things, when I didn't set them off.

Mr. Chairman, I want to thank you for the opportunity to appear before the subcommittee today and register my support for a continued Federal investment in research, which will

allow the remarkable progress and achievements in musculoskeletal research to continue. I believe these are the ``good old days'' of medicine, right now, and I'm sure they're going to get even better.

Thank you.

Mr. Porter. Thank you, Mr. Downs.

Can I ask the doctor what the 60 percent reason is? Because you've got my curiosity up.

Dr. Ehrlich. Women do have a higher incidence of osteoarthritis, sir, than men in the population. In fact, it will afflict about one out of every four adults over the age of 45. That is why the incidence is high.

Mr. Porter. I think I will launch into ``sermonette number one,'' if I may, and simply say that this subcommittee has put biomedical research, as you may know, at a very, very high priority. We think that it is among the best-spent money in America in Government because the payback in health care cost savings is huge, and the improvements, obviously, in the quality and length of life are evident to anyone who looks at it.

I believe that the subcommittee will continue to put it at a high priority. Many of our witnesses have been testifying that what we really ought to do--and we agree with this--is to increase funding for biomedical research, indeed all basic research funded by Government, double over the next five years.

I believe that this is possible to do, but it depends in large part on what the Budget Committee gives us to work with. I have been asking all of our witnesses to consider that impacting the budget process, as well as impacting the appropriations process, is very, very important in determining what we have to work with and what we can do in respect to funding biomedical research.

So I am asking all of you to go see John Kasich and tell him that this is important, and perhaps we can get the kind of allocations that will allow us to do the kinds of things that we think are necessary to provide the resources to our research scientists who engage in further breakthroughs in all these areas. They can make a real difference in people's lives.

We can't tell you how much we appreciate your coming here to highlight this for us. I think it makes all the difference with the American people; after all, the policies that are done in Washington are done in response to what the American people want us to do, and if they believe that this is a high priority, it will find its way at the highest priority in our deliberations.

Mr. Stokes.

Mr. Stokes. Thank you, Mr. Chairman.

Mr. Chairman, I don't have any questions, but I certainly want to take this opportunity to express my appreciation to Mr. Downs for his appearance here today and to say to him that I, like so many other Americans, have sat in front of my TV set on so many occasions and admired the manner in which you have brought the news and other commentary into all of our homes.

I also might share with you the fact that, being a grandfather, a few years ago I was trying to play basketball with 10-and 12-year-old grandsons, and in trying to show off and make a three-pointer, I threw one knee out of place and

wound up with arthroscopic surgery. The tragedy was, I didn't make the shot. [Laughter.]

It's a real pleasure to have you here. Thank you so much.

Mr. Downs. Thank you so much.

[The prepared statements of Hugh Downs and Michael G. Ehrlich, M.D., follows:]

[Pages 1377 - 1394--The official Committee record contains additional material here.]

Tuesday, February 3, 1998.

WITNESSES

DR. DEBORAH PROTHROW-STITH, M.D., NATIONAL COALITION OF SURVIVORS OF VIOLENCE (YOUTH VIOLENCE PREVENTION)

HELEN BASSETT

Mr. Porter. Dr. Deborah Prothrow-Stith, Associate Dean and Professor, Harvard School of Public Health, representing the National Coalition of Survivors of Violence, Youth Violence Prevention.

Dr. Prothrow-Stith.

Dr. Prothrow-Stith. Thank you very much, Chairman Porter, for allowing us to come before the subcommittee. I want to have this opportunity to give particular thanks to Congressman Stokes for his work on health. When I heard that he was retiring, I knew that one of the Generals in the efforts to promote health in America would be retiring.

I want to wish you the best, but I want you to know how much we're going to miss you. We hope that you will enjoy retirement and keep us in your prayers as we continue some of this work. We will come to see you and get your advice, but we will miss you, and I wanted you to know that.

What we would like to do this morning is share with you three things.

The first is that the epidemic of youth violence in the United States, considered a public health epidemic, is not over. We have been celebrating reductions in violence and violent crimes in the United States; those reductions are primarily among adults. Young children and teenagers are still becoming more and more involved in some pretty tragic episodes. Now is not the time to retreat. We have some prevention that works, and now is the time for the Federal Government to continue the kind of efforts that it has put in this regard.

The second point is that prevention works. Across the country we have school-based programs, community-based programs, collaborations between public health and police and social service agencies that work, and Boston is an example of this. We had two and a half years in Boston where we had zero deaths to children 16 and younger by firearms. We had had 30 in the three years prior. It is remarkable that we had zero. And policing has something to do with what happened in Boston, but for 15 years public health people and community people have been working with police, and really set the stage for that decline.

The second point is that success can work. Prevention can work; we've had those successes, and Boston is an example.

The third point that I would like to make is that Federal agencies have been working together in a way that is pretty remarkable and somewhat new. We are really impressed with the way DOE, CDC, OJJDP and NCH have come together to do some training around violence prevention and to fund that. It is important because CDC's Injury Center really reflects the growth in looking at violence as a public health problem, and those successes are directly connected to that growth.

I have with me Helen Bassett, who is from Minneapolis, and is the founding treasurer of the National Coalition of Survivors. This group reminds me of Mothers Against Drunk Driving. The issue of violence for them is one that we must continue to address, and I would like her just to say a few words.

Ms. Bassett. Thank you.

Good morning, Mr. Chairman and panel. I, too, will miss you, Congressman Stokes, and my best to you as well.

I am happy for this opportunity and I am thankful to Dr. Prothrow-Stith for her work that she does in violence prevention. She is a champion for us who are out in the communities, losing children.

I wanted to say that in Minneapolis, you may have heard, we have had some success as well. Attorney General Janet Reno was in Minnesota two weeks or so ago and applauded the efforts of the public-private partnership there. I am active with the group that she brought lauds to, Minnesota Heals, and what I would say is that the prevention side of that are partners around the table in Heals, which includes business and public health and others. We have the resources for law enforcement and we're happy for those. We need help on the community side for public health and for prevention, because it's parents like myself who have lost loved ones who could easily go the way of prosecution and talk about more punishment, but in the end, in the long term, is that really going to save our children? The answer to that is no.

We want to save our children, make no mistake about that, and we are ready to partner with whomever we need to partner, if that's law enforcement, if that's business. Whoever that is, we stand ready, but we cannot partner without adequate resources, and those resources we want in prevention and intervention, because our kids can be saved. They are not a lost generation; they are not unsalvageable. At 9 years old, 10 years old, 12, 13, 14, they are still children, just as your children are still children and just as your grandchildren are still children. They are our children, and we absolutely want them saved.

Dr. Prothrow-Stith. We will be working with Congressman Stokes' staff to really think about the appropriation for CDC and the Injury Center in particular, but we really appreciate this opportunity to make sure that the issue stays on your agenda, and say that the epidemic is not over. There may be a second wave in rural communities and a third wave involving girls and violence. Now is not the time to stop our efforts.

Thank you.

Mr. Porter. Thank you very much. We hear what you're

telling us and its importance. We will do the very best that we can to provide the resources that are needed to get us past this ongoing problem for our country and for our kids. I think all of us feel that way. You already heard my sermonette about how we get those resources, but we'll do our very best.

Thank you for testifying.

Mr. Stokes.

Mr. Stokes. Thank you, Mr. Chairman.

I would just like to take a moment to express my appreciation both to Dr. Deborah Prothrow-Stith and to Ms. Bassett for their very kind and warm remarks.

But also to say, Mr. Chairman, that I've had the pleasure over a number of years now working directly with Dr. Stith. I am very appreciative of the fact that I've had the benefit of her counsel and her expertise, particularly in the area of violence and violence prevention, in the work that she's done with reference to violence in the African American community as it relates to youth. Of course, she is also the author of a very excellent work relative to this subject.

I just want to say to both of you that it's a pleasure to have had you here this morning. I don't know of any subject that is more important than preventing violence in our society, and I appreciate the reception that the Chairman has given you. I'm sure we'll work with him to try to see if we can't do even more in this area in terms of our appropriations process.

Thank you very much for coming.

Dr. Prothrow-Stith. Thank you.

Mr. Porter. Thank you, Mr. Stokes.

[The prepared statement of Deborah Prothrow-Stith, M.D., follows:]

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

[Pages 1398 - 1400--The official Committee record contains additional material here.]

Tuesday, February 3, 1998.

WITNESS

ARNOLD MITCHEM, NATIONAL COUNCIL OF EDUCATIONAL OPPORTUNITY ASSOCIATIONS

Mr. Porter. Our next witness is Dr. Arnold Mitchem, Executive Director, National Council of Educational Opportunity Associations, testifying on behalf of those associations.

Dr. Mitchem.

Dr. Mitchem. Good morning, Mr. Chairman, members of the subcommittee----

Mr. Porter. I'm sorry, I neglected to recognize my colleague from Texas, Mr. Bonilla.

Mr. Bonilla. Thank you, Mr. Chairman.

I would just like, before you offer your testimony, to point out to those on the subcommittee who may not know your

background and what you're doing, and for those who are here with us at the hearing today, about the outstanding work that you're doing and how you overcame such great odds. I know that you are known officially, of course, as Dr. Arnold Mitchem, but most of your friends call you Mitch. A lot of people may not know that you overcame significant odds to be where you are today, having helped so many young people in communities across the country. Growing up in the 1940s and 1950s on Chicago's West Side, then you had a case of polio when you were younger which also caused you to not have as much use out of your arm as you would like to have, and in spite of having all those things going against you, you graduated from the University of Southern Colorado and then received your Ph.D. from Marquette.

The National Journal--I enjoyed that article about you recently--did a wonderful piece entitled, ``Making Miracles, One at a Time.'' I think that's an appropriate title for the work that you do, and specifically with the TRIO program that your organization has strongly represented.

As you know, I can identify with you to some degree. I was also born in a housing project on the west side of San Antonio. No one in my family had ever had an opportunity to attend a university. The TRIO program helps students that come from families like yours and mine to get that first step to go to college. It's a transitional program in which I believe very strongly. It just helps give you that boost to get started; it's almost like getting a jump start, to get your life going into a university.

I thought people should know that today before you began your testimony, so welcome, Mitch.

Dr. Mitchem. Well, thank you very much, Mr. Bonilla. That was very kind and it is deeply appreciated. Thank you.

Mr. Chairman, members of the subcommittee, on behalf of the National Council of Educational Opportunity Associations I wish to thank each of you for your support of postsecondary education, and the TRIO programs in particular. I would also like to take this opportunity to acknowledge you, Mr. Stokes, for the historic role that you have played over the decades in building a very strong and positive consensus for these programs.

I want to make two points today. First, we need to invest in TRIO programs in order to ensure that more TRIO students can succeed in a more complex and expensive higher education environment.

Second, we need to take a serious look at the erosion of per student funding, particularly in Student Support Services, and its connection with the retention of low income students in higher education.

Now, in order to expand the services provided by TRIO programs to reach more students, and to provide more intensive services, NCEOA is requesting a \$655 million appropriation for fiscal year 1999. This increase will allow TRIO programs to serve an additional 51,000 youth and adults who are seeking or who are currently pursuing a college education.

Before I go any further, I want to pause again to applaud the steps this subcommittee has taken in past fiscal years to increase resources which help needy students attend and graduate from college, for increasing the maximum Pell Grant to an all-time high

of \$3,000, for increasing work study funds, and, of course, for increasing the TRIO funding to \$529.6 million, with the significant role that this committee played in conference with the Senate last year. In my view, your dollars have been well spent. In the case of Upward Bound, national evaluations show us now that Upward Bound makes a difference in a student's aspirations and preparations for college. We also know that our Talent Search and Educational Opportunity Centers continue to play a vital role in advising low income families and providing supplemental educational services. The latter, gentlemen, is critical, because studies show that without some intervention, only 28 percent of students from low income families complete the college prep sequence, compared to 65 percent of upper income students who do so without any intervention. No doubt, with increased support Talent Search will enable more low income students to complete a college prep curriculum.

My second point is that over the past two decades the number of Student Support Services projects has grown dramatically, from 121 to over 800 today, and the number of students served per year from 30,000 in 1970 to more than 175,000 today. The national evaluations of Student Support Services programs show that these programs are having a highly significant effect in terms of the retention of their students in college. Students in Student Support Services were 22 percent more likely to be retained through their third year of attendance at the college where they began than were similar nonparticipants, and had a 77 percent chance of continuing for a third year in college.

The last point is especially significant and stands in sharp contrast to some data we have from the National Center for Education Statistics. They found that more than 53 percent of students from the lowest income quartile who entered college had not achieved a degree or a certificate and were no longer enrolled four years later.

The ability of Student Support Services programs to continue to have such a dramatic impact on the retention of low income students depends upon their ability to deliver intensive and effective services. This ability, gentlemen, stands at risk today, and it stands at risk because the funding for Student Support Services participants has declined from its peak in 1990 dollars of \$1,123 in 1970, to a low of \$507 per participant in 1981. For fiscal year 1996, the per participant funding is now \$867.

Thus, I ask you to take this into consideration as you consider our request.

Again, Mr. Porter, Mr. Bonilla, Mr. Stokes, thank you very much for giving me this opportunity.

Thank you again, Mr. Bonilla, for those very, very kind comments.

Mr. Porter. Thank you, Dr. Mitchem.

I think you have in Mr. Stokes and Mr. Bonilla two really strong advocates for the programs that you have mentioned. Lou has been there on the TRIO program, and the members of the subcommittee believe that it is one of the best programs that we know of for getting results for young people, and have been very supportive. Henry, of course, has been there very strongly on our side of the aisle.

I think that in our deliberations there are going to be at

least two strong voices, and maybe more. All of us hear you very strongly and appreciate very much your coming here to testify and reminding us of the importance of these programs to young people.

Dr. Mitchem. Thank you very much, Mr. Porter.

Mr. Porter. Mr. Stokes.

Mr. Stokes. Thank you, Mr. Chairman. I will just take a moment.

I would just like to concur with the accolades that were accorded you by Mr. Bonilla. I certainly cannot improve upon the fine treatment he gave of what you have meant to this country and to the field of education. In the years that I've worked with you, I don't know of anyone in the field of education in this country for whom I have greater respect and higher admiration than I have for you.

At the same time, I want to commend Chairman Porter and the other members of this subcommittee. While for years I have been an advocate on behalf of TRIO programs, the type of increases that we've received over the years could not have been achieved had it not been for the receptivity on the part of the Chairman and the other members of this subcommittee, all of whom have been very sensitive to the types of concerns that you have expressed here today. During the time that I am accorded here, the rest of this term, I look forward to working with them in trying to continue that type of response to the needs of disadvantaged, and in particular minority, children who fall in this range.

Thank you very much.

Mr. Porter. Thank you, Dr. Mitchem.

[The prepared statement of Arnold L. Mitchem follows:]

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

[Pages 1404 - 1409--The official Committee record contains additional material here.]

Tuesday, February 3, 1998.

WITNESS

NINA SHOKRAII, REPRESENTING HIMSELF

Mr. Porter. Our next witness is Nina Shokraii, Education Policy Analyst, The Heritage Foundation, testifying on her own behalf.

Ms. Shokraii. Mr. Chairman and members of the committee, thank you very much for inviting me today to discuss with you ways to reform education programs within your committee's jurisdiction. I will concentrate on three specific programs, and I offer my recommendations on how to make them more effective by sending them to States--and, more importantly, to families and parents.

The programs that I am going to focus on are impact aid, bilingual education, and Title I.

With impact aid, I recommend voucherizing and sending the entire program to the Department of Defense. This program was established during World War II, providing support to school districts affected by Federal activities, mostly related to relocation of military personnel.

Because Federal lands are not subject to local taxation, local education agencies receive payments to compensate for revenue losses that resulted from the Federal Government's acquisitions of significant portions of their district's tax base. Today the program receives about \$615 million, and it has really, in our opinion, outgrown its usefulness. Since this program is largely designed around children of Federal Government workers who tend to relocate a lot, we feel that it's best to tie the money to the children who move around with their parents from one military base to another military base, and I would like for the money to follow the child from the school to any school of choice, be it public, private or parochial. Transferring this money to the Department of Defense at a \$1,000 voucher per child as part of an expanded compensation package would save an average of \$285 million. It would also assure that the areas most affected by this influx of students receive the most amount of money.

The second program I will focus on is bilingual and immigrant education. We recommend block granting it to the States. This program was started in 1967 as part of the Elementary and Secondary Education Act. Initially, Congress did not limit bilingual education support to any one particular instructional method. As you know, in 1974, upon the establishment of the Office of Bilingual Education and Minority Languages, this policy was reversed. Congress mandated at that point that schools use transitional bilingual education instruction methods by which students are introduced to English while receiving their coursework in their native tongue. The Department of Education itself has found that using this method has so far been detrimental to the extent that it takes the kids about six additional years to learn English.

Now, the Federal dollars really are only 3 percent of the entire budget of bilingual education, but the Federal mandate and influence in local school districts has made it so that a lot of these school districts are relying more and more on bilingual education instead of other instructional methods. This is actually despite a lot of Hispanic opposition to this program. I'm sure you've heard of the California initiatives by now. Last February, dozens of working-class Latino parents boycotted a school in Los Angeles, protesting that they basically did not want their kids taught in bilingual education courses because they were not learning English. As a result, there was an initiative on the California ballot this year which gives the option of enrolling children in bilingual education courses to the parents of those children. Support for this initiative, according to the Los Angeles Times in October, was 84 percent amongst Latino parents.

By sending this \$261 million program to States, the Governors can use the money to develop whatever programs they deem most appropriate and effective in teaching English as a second language, not one mandated by the Federal Government.

Finally, with Title I, we are big advocates of voucherizing

this program. This program provides funding for local education agencies and schools in areas with high poverty rates. The program benefits approximately 5 million low-achieving students, but unfortunately, three decades and over \$100 billion later, the only two longitudinal studies of the program have shown that this program has not been successful in helping children overcome poverty's negative impacts.

As you know, we are big advocates of school choice. The only two school choice programs existing in this country that help low income minorities primarily are in Milwaukee and Cleveland, and the studies of those programs by Harvard Professor Paul Peterson and University of Texas at Austin Professor Jay Greene have shown that both of those programs are extremely beneficial in teaching low income kids and increasing their academic achievements. In Milwaukee, for instance, the researchers concluded that after staying in the program for five years, the gap in test scores between whites and blacks--and minorities, excuse me--narrowed by 33 to 50 percent, to the point that if these trends continued, that gap would ultimately disappear.

In Cleveland, the researchers studied two specific schools that were solely designed to take care of the vouchered children, and they found that the kids who were accepted to this school increased their reading scores by 15 percentile points and their math scores by 5 percentile points, just after being in the program for a year. Now, a year is really not long enough to measure anything, but studies have shown that in the inner cities, especially in places like Cleveland, just being able to maintain your test score at the level that it was when you first started is a big accomplishment. So the fact that these children did better by these percentile points is extremely significant.

Mr. Chairman, sending these three programs to States as a block grant, or to families as a voucher, instead of bureaucrats, will save the American people money while improving the academic futures of our children, especially those from disadvantaged backgrounds.

Mr. Porter. Ms. Shokraii, thank you for your testimony. I have to say that you are in the wrong store. We are appropriators and we have to do what the authorizers tell us, and until we have authority to do the kinds of things that you've suggested, making Title I a voucher program and basically the same with bilingual and impact aid, we have to continue funding them through the existing programs that are authorized by law.

So your message is really one, in the first instance, at least, for the authorizing committee that sets up the law.

Let me say that a lot of what you said, I agree with, and I think other members of the committee do; others don't. Let me talk about impact aid, though, because this is a subject that I think I know a fair amount about.

Impact aid ought to be, in my judgment, an entitlement program. It's an absolute obligation of the Federal Government to support kids whose parents don't pay the local property taxes that fund the school system, and I think the Federal Government has to meet that obligation. I have in my district the largest primary naval training facility in the world at

Great Lakes in North Chicago, Illinois. Like many military bases, the community around it is a very poor community, the third poorest in our State. They don't have a good base on which to tax in the first place, and with 50 percent of the kids in the school system coming from the military base, they absolutely are dependent upon the Government providing some share of the funding, or the school system could not exist. In fact, it almost went bankrupt about four years ago when the Federal Government payments were so low that it actually voted itself into bankruptcy because it had no funds left, until we could straighten that out.

You might think that Defense wants this program. They absolutely do not. They don't consider themselves responsible for the education of military kids; they think that's a local responsibility, which it is, and they don't want to get involved with it. Therefore if you tell Defense that you want them to take the program--I'm talking about our colleagues in the committees--they will say, ``No way, we don't want it.''

So if I were to make a change in this program, I would make it an entitlement. I would suggest, by the way, that a \$1,000 voucher is way, way short of what the Federal Government has to provide for kids. In this very poor school district that I just described to you in North Chicago, in one of the poorest cities in Illinois, the cost of educating that child is about \$6,500, and that's about the lowest in the region. And \$1,000 would not do anything to get that kid that education because, again, the school system would simply go bankrupt. It's way short of the Federal Government's obligation, and thank goodness we are providing more money than that, and not shifting the costs of those kids onto local taxpayers who simply can't afford it.

That was sermonette number three, I think.

Anybody else? Mr. Miller.

Mr. Miller. I'm glad that we actually have speakers coming before the committee that raise questions about how we spend money, and I commend you for allowing them to participate in this process because, as you know, 98.5 percent--or something like that--are here advocating more spending and more programs, which are good programs and we do support them. But we need to have organizations and individuals willing to step forward and say, hey, we should look at some of these programs.

I admire you for coming. I appreciate it, and thank you for being here today.

Mr. Porter. Let me emphasize that, Dan.

I think Mr. Miller is absolutely right. We've had a number of witnesses now from Heritage and from AEI and others who are interested in this process and giving us their analysis, and you're one of them, and we very much do appreciate it. I wish we could respond to some of the things you said. The bilingual program, for example, I think you're exactly right on that. I think Henry would agree with what you said, although I certainly don't speak for him. But our subcommittee doesn't have the authority to do what you want us to do, and you've got to get Bill Goodling's subcommittee to look into these matters and see if they can make some changes that make sense for the country and for the kids that we serve.

Thank you very much.

[The prepared statement of Nina Shokrai follows:]

Tuesday, February 3, 1998.

WITNESSES

VERA DORSEY, CITY OF COMPTON, CALIFORNIA

ROBERT THOMAS

Mr. Porter. Vera Dorsey, Director, Department of Employment and Training Services, testifying on behalf of the city of Compton, California.

Ms. Dorsey. Good morning. I bring you greetings from the city of Compton, from the Mayor, City Council and the citizens of Compton, California. We thank you for the opportunity to be here today to testify.

On a personal note, from my Mayor, Council and citizens, Mr. Stokes, we learned recently of your retirement, and I was asked to make sure that they give you warm wishes for a healthful, restful, peaceful, and relaxed retirement.

Mr. Chairman and members of the subcommittee, on behalf of the Mayor and City Council of the city of Compton, California, I would like to thank you for the opportunity to provide testimony related to the city's Department of Employment and Training Services, also referred to as DETS, and the pervasive and very serious challenges facing our community, reducing illiteracy, unemployment, and moving many of our residents from welfare to work.

For the sake of time, I have abbreviated my written remarks, and I urge the members of the committee to review my full statement when time permits.

Mr. Chairman, last week the President stood before a national audience and proclaimed that America was experiencing record economic growth and low unemployment. Unfortunately, the rising tide of economic prosperity has yet to reach the battered shores of Compton, California. While we are resilient and determined to bring about an economic regeneration within Compton, city leaders continue to grapple with a stagnant local economy and double digit unemployment levels. While the Los Angeles County unemployment rate is 5.8 percent, and the State and national rates are 5.5 and 4.4 percent respectively, the unemployment rate in Compton is an appalling 14.7 percent, three times the State and county rates and nearly four times the national rate. Additionally, more than 40 percent of the city's residents receive some type of public assistance.

Over the last two years, DETS has been working towards redesigning its service delivery system in response to Federal and State initiatives geared toward development of a nationwide career center system. DETS is slated to open Compton's one-stop career and human services center this summer. At the same time, the agency is preparing to mount a slate of services for hard-to-serve welfare clients under the new welfare-to-work program passed last year by Congress. Under this workforce program, DETS will provide services which will aid welfare clients in becoming self-sufficient by

transitioning them to employment opportunities which offer long-term job retention.

Clearly, the program priorities described above provide DETS with ample challenges and a significant workload. Moreover, management and staff are acutely aware that the current financial resources are still insufficient to meet the overwhelming employment and training needs of the community. It is in this vein, Mr. Chairman, as the committee considers funding priorities for fiscal year 1999 Labor/HHS/Education appropriations bills, that the city of Compton respectfully urges the committee to support the following recommendations.

Number one, Compton urges the committee to support, above the Administration's fiscal year 1999 request, funding for youth training grants proposed at \$130 million, and summer youth employment and training programs proposed at \$871 million, as well as providing funding for new out-of-school youth programs proposed at \$250 million.

Over the last several years, Federal workforce funding for youth programs has vacillated. With nearly 30 percent of Compton residents between the ages of 13 and 20, DETS continues to struggle to identify solutions for youth employment needs in light of decreased and unstable Federal youth funding. Increased youth funding is desperately needed in order to promote a positive work ethic in youth during their high school years. Such programs also serve as a means of promoting diversion activities for adjudicated youth and others who are at risk of dropping out of school or participating in nonproductive or illegal activities.

Number two, Compton recommends that the committee continue to support adult training grants, proposed at \$1 billion, and increase the Federal one-stop career center program, proposed at \$146.5 million. Recently, Congress has attempted to pass legislation to consolidate a wide variety of Federal unemployment and training programs. As stated previously, Compton has taken a leadership role in developing a one-stop center delivery system for its residents; however, this role has brought the financial burden of covering the lion's share of costs for implementing and maintaining the center and associated support systems. Although Congress has made recent appropriations for one-stop system development, additional resources are needed to ensure that all local centers have sufficient financial resources necessary to operate a well-functioning one-stop system of delivery.

Compton recommends that the committee continue to support the Department's welfare-to-work initiatives.

Finally, Mr. Chairman, Compton requests that you support the Administration's request for \$250 million, to be split evenly between the Department of Labor and the Department of Education, for the purpose of school-to-work, and \$1.5 billion for educational opportunity zones that will aid urban and rural schools with high concentrations of children from low income families.

Mr. Chairman, this concludes my testimony. Again, thank you for the opportunity to express the views and recommendations of the city of Compton, California.

Are there any questions?

Mr. Porter. Ms. Dorsey, thank you for your testimony.

I was asking the staff to provide me with the figures in the President's budget, but my recollection on youth training, for example, and summer youth, was that the President had level-funded those from the previous year, and that on one-stop, he had actually cut it. I may be wrong; I'm trying to get the figures right now. Is that what you saw in his figures?

Ms. Dorsey. I'm not quite sure that it had been cut.

Mr. Porter. I was surprised when I saw them because I thought the President would put them at a higher priority, and he hadn't in his own budget. The difficulty often in Congress is that if the President doesn't give weight to these kinds of programs, Congress tends to take his advice on it. So I'm a little bit concerned about his budget on these items.

Mr. Thomas. Mr. Chairman, I'm Robert Thomas, from the City Council as well.

Mr. Porter. Yes.

Mr. Thomas. We do realize that he did ask for level funding, but if you would look in Ms. Dorsey's full statement, she outlines why there is a need for increased funding for both those programs pertaining to youth training, as well as summer jobs. I think she touched on it briefly in her statement, saying that roughly 30 percent of Compton's residents are between the ages of 13 and 20. Most of them, especially during the summer, have nothing to do, and as you know, there are plenty of other things to do for kids outside of doing the right thing. What we're trying to do is bring about a positive change; instead of being involved in gangs and drugs, to have programs that they can come into and get involved with. I don't know if you know, but Shaquille O'Neal has just opened up a manufacturing plant and has hired kids and has them working within Compton----

Mr. Porter. That's great.

Mr. Thomas [continuing]. There are a lot of children who have never worked and who have dropped out of school who are now considering going back to finish their education because they've received a job from this plant and other activities.

Mr. Porter. You know what I would like to see, and maybe I'm wrong in this--you can correct me if I am--but I think often, and this applies to a lot of different programs, we've gone through a process over a number of years of trying to attract votes for programs by giving some of the money to everybody. I'm not sure that these programs are on that formula, but I can tell you this, that I think we've got to get over that. We've got to put the money where the problems are, and we've got to address those problems forcefully instead of sending the money all of the country where, in some places, it's not needed at all; it simply makes their local tax burden less.

Mr. Thomas. That's what we're saying about the unemployment.

Mr. Porter. Exactly. You've got serious problems that need to be addressed; you need the resources, and in many cases we're sending them places that don't need them at all. I can't do anything about that as an appropriator, but I would hope that you would also--I just told the previous witness the same thing--impact Mr. Goodling and the authorizing committee that have authority over these matters, because I think we need to

do a much better job of targeting these resources to where they are most needed.

Mr. Stokes.

Mr. Stokes. Mr. Chairman, you're absolutely correct, and they're absolutely correct. The problem is a political one, as you and I know. Oftentimes for these types of programs, in order to get them passed to affect the areas where they're needed, we've got to get the votes for them. Therefore, the money winds up going to other places where it's not even needed.

Mr. Porter. Lou, I would hope that somehow we're past that, but you probably are right. I just hope this country gets the idea that we've got to get these problems solved.

Thank you both for your testimony.

Ms. Dorsey. Thank you very, very much.

Mr. Porter. You came a long way to testify, too.

Ms. Dorsey. It's very important to us.

Mr. Porter. That means it's important, right.

[The prepared statement of Vera Blanche-Dorsey follows:]

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

[Pages 1422 - 1428--The official Committee record contains additional material here.]

Tuesday, February 3, 1998.

WITNESS

DR. JOHN L. SEVER, M.D., ROTARY INTERNATIONAL

Mr. Porter. Dr. John Sever, Professor of Pediatrics, Children's National Medical Center and George Washington University Medical Center, testifying on behalf of Rotary International.

Dr. Sever, nice to see you.

Dr. Sever. Nice to see you, sir.

Chairman Porter, Mr. Stokes, members of the subcommittee, thank you for this opportunity to testify on behalf of Rotary International in support of the effort to eradicate polio and the activities of the U.S. Centers for Disease Control and Prevention. As you mentioned, I am Dr. John Sever; I am Professor of Pediatrics and Infectious Diseases at the Children's National Medical Center here in Washington, D.C., and I am here today representing a broad coalition of health advocates for children, including Rotary International, the March of Dimes Birth Defects Foundation, the American Academy of Pediatrics, Task Force for Child Survival and Development, and the U.S. Committee for UNICEF, to seek your continued support for the global program to eradicate polio.

Allow me first, on behalf of Rotary International and the coalition, to express our sincere gratitude to you and this committee for your support. For 1997 and 1998, you recommended \$47.2 million be allotted each year for polio eradication

activities of the Centers for Disease Control and Prevention. This investment makes the United States the leader among donor nations in the drive to eradicate this crippling disease.

The target year is the year 2000, and that's a thousand days remaining between now and the end of year 2000, to defeat this disease in countries where the polio virus still causes death and disability. The eradication of polio has been and will be achieved through your leadership, and it will not only save lives but also save our financial resources.

Eradicating polio will save the United States at least \$230 million annually. We must continue to immunize children in this country for polio, although there has been no polio in this hemisphere for more than five years. When polio is eradicated worldwide, however, which we're very close to, we will be able to stop immunization, and this will result in an average saving of over \$230 million annually.

Thanks to your appropriations, the international effort to eradicate polio has made tremendous advances during the past two years. Preliminary estimates that are reported for polio cases in 1997, the last year that this information is available for, indicate there were approximately only 3,500 cases anywhere in the world, and we're well on the way to eradicating polio by the year 2000, as has been projected.

The CDC is participating very actively in eradication efforts, particularly in those two areas where polio remains, South Asia and Africa. The United States' commitment to polio eradication has stimulated other countries to increase their support. Belgium, Canada, Finland, France, Italy, Korea, Norway, Sweden, Switzerland, Japan, Australia, Denmark, and the United Kingdom are among those countries which have followed America's lead and have recently announced special grants for polio eradication.

By the time polio has been eradicated, Rotary International will have expended over \$400 million on that effort. This is the largest private contribution ever made to a public health initiative.

For fiscal year 1999, we respectfully request that you provide \$67.2 million for the targeted polio eradication efforts of the Centers for Disease Control and Prevention. This is an increase of \$20 million over the fiscal year 1998 level, and it is \$20 million more than the President's fiscal year 1999 budget request, which was submitted by the President before WHO released the latest estimates of unmet polio eradication needs. The additional \$20 million is particularly needed to meet the enormous costs of eradicating polio in its final pockets of strongholds, in sub-Saharan Africa.

Of this amount, \$6 million would be used to purchase vaccines which are needed for these mass immunizations; \$5 million would be provided for operational support of national immunization days in countries such as Liberia, Somalia, and the Democratic Republic of the Congo, which are difficult countries to work in but need to have the disease eradicated to complete the job.

A further \$9 million would go to develop an Africa-wide polio surveillance system and strengthen and expand the existing network of regional and national laboratories to document the eradication of polio.

Without this additional appropriation, we may not be able to eradicate polio by the target date.

In conclusion, polio eradication is an investment, but few investments are as risk-free or can guarantee such an immense return. The world will begin to break even on this investment in polio eradication only two years after the virus had been vanquished. The financial and humanitarian benefits of polio eradication will then accrue forever. This will be our gift to the children of the 21st century.

I thank you for this opportunity to testify and I appreciate your support.

Mr. Porter. Dr. Sever, first let me apologize because I think I have mispronounced your name two or three times, and the reason is that I know someone with the same name at home who pronounces it Sever. It's SEV-er.

Dr. Sever. Thank you, sir. I answer to anything.

Mr. Porter. Secondly, I'd like to say how strongly I admire the work of Rotary International in taking on this tremendous challenge, and the success that you've achieved and the resources that you've put into it. I think Rotary is on what I consider the cutting edge of the future in public-private partnerships to achieve specific worthwhile ends. I think it's an example for other organizations across our country as to what can be done if people work together. You, of course, have a worldwide membership, but people working together can really put their sights on getting something accomplished. You've just done a wonderful job, and we on the subcommittee want to continue to be as supportive as we possibly can. I can tell you that we will do our very best to do exactly that.

Dr. Sever. Thank you, sir.

Mr. Porter. Thank you, Dr. Sever.

[The prepared statement of John Sever, M.D., follows:]

[Pages 1432 - 1440--The official Committee record contains additional material here.]

Tuesday, February 3, 1998.

WITNESSES

GLORIA E. REICH, AMERICAN TINNITUS ASSOCIATION

DAN PURJES

Mr. Porter. Gloria E. Reich, Executive Director, American Tinnitus Association, testifying on behalf of the association.

Dr. Reich.

Ms. Reich. Good morning, Chairman Porter.

I am hearing impaired and I experience tinnitus. It is a condition that is shared by more than 50 million Americans. With me today is Dan Purjes from New York. Dan is Chairman of Josephthal & Company and Hearing Innovations, Inc., and a member of our board of directors. In just a few moments he will tell you about his tinnitus.

Tinnitus is most often described as the perception of sound when there is no external sound present. It can take many forms and be described in many ways. It can strike people of all

ages, and for the most part, it doesn't go away.

For the 50 million Americans who experience tinnitus, about 10 million to 15 million suffer severely and seek help through the health care system. There are still many questions that remain unanswered. The mechanism that causes tinnitus is unknown, and that fact alone makes it impossible to properly diagnose and treat this elusive symptom.

Furthermore, the personal and social consequences of tinnitus, particularly depression and anxiety disorders, have generally been ignored in favor of a more strictly hearing-based approach, relying on the definition of tinnitus as a symptom of auditory dysfunction. Many people who are the most troubled by tinnitus have relatively normal hearing and are thus deprived the cachet of a legitimate illness. Their head noises are for the most part subjective and idiopathic, and poorly understood, not only by themselves but by the health professionals who treat them.

The mission of the American Tinnitus Association is to promote relief, prevention, and the eventual cure for tinnitus for the benefit of present and future generations. Since our inception in 1971, we have seen more than 3,000 scholarly papers, a dozen books, and the formation of workshops, seminars, and support groups to aid tinnitus management. Effective treatments for tinnitus have also proliferated, and most patients can now expect a reasonable degree of relief for this symptom. However, from the point of view of the tinnitus sufferer, research still hasn't produced a cure, and a cure, let me assure you, is what sufferers want.

Three years ago the National Institute on Deafness and Other Communication Disorders conducted a tinnitus workshop and recommended strategies for research. Last year they funded five studies about tinnitus that addressed these issues. Most recently, they awarded \$1.5 million to Doctors Salvi and Lockwood in Buffalo, New York, to study the activity in the brain that may be triggering tinnitus. The Salvi-Lockwood studies and four of the five previous studies were initially funded by ATA with grants that enabled the investigators to produce the pilot data necessary to qualify for Federal grants. These events represent a great stride forward for tinnitus research within the NIDCD, and for that we are truly grateful. Just five years ago the word ``tinnitus'' was not even mentioned in the NIDCD plan.

The tinnitus community is very grateful to you, Congressmen and Congresswomen, for providing the necessary funding for the NICDC to undertake these projects. We hope this is just the beginning.

It is extremely important for Congress not only to fund medical research, but to require that the Institutes receiving that funding really respond to the public's need. Hearing problems, and tinnitus specifically, are the most prevalent health issue in this country, but receive little attention in comparison to the more visible life-threatening diseases. Additionally, in an effort to contain medical costs, insurers--both public and private--effectively deny most people treatment for their hearing problems.

We know people are concerned because whenever there is a public mention, our phone lines ring off the hook. This week we

have received thousands of calls just from one mention in a syndicated column.

There is a great social cost on society from tinnitus. Up to 15 percent of the people who have it are forced to change jobs or quit their jobs, and these people could be productive members of society if they were relieved of that problem. We ask you to generously support the funding for the National Institute on Deafness and Other Communication Disorders, and to urge them to fund more studies about tinnitus.

Now I would like to introduce Dan Purjes.

Mr. Purjes. Congressman Porter, thank you for the opportunity to address the committee.

A few months ago my friend, an attorney, called me late one night, saying he was sitting on the edge of his bed with a revolver in his hand, about to blow his brains out. He had just come down with tinnitus, with a ringing sound in the ears, it made his life unbearable. Doctors told my friend he may have to live with tinnitus for the rest of his life, and he could not face the prospect of lifelong suffering.

Over 30 years ago my hearing was damaged in a head injury. Since that time I have had to live with this constant high-pitched hissing sound in my head, 24 hours a day, every day of the year.

It is urgent that you support the research of the National Institute on Deafness and Other Communication Disorders through increased funding. People are dying by their own hands, and many more are suffering endlessly while they hope for a cure. I'm one of the lucky ones; I've learned to cope with this condition, though it interferes with my hearing. Many others are so intensely afflicted, the sound in their head is so loud and debilitating, that they end their lives because today there is still no glimmer of a cure. Fortunately, my friend was not one of them, but how close he came that night when he called for my help and understanding, I will never forget. I ask that you give your understanding and help.

It is estimated that over the coming years, something like one-third to one-half of all Americans will suffer hearing impairment of one kind or another. I have been active in this field, and we desperately need additional funding for more research.

Thank you.

Mr. Porter. Mr. Purjes, thank you very much for your testimony.

Dr. Reich, do you suffer from this disease also, personally?

Dr. Reich. I hear the tinnitus, yes; is that what you're asking?

Mr. Porter. Yes. I'm asking whether you have tinnitus, as well.

Dr. Reich. I consider myself one of the people who are naturally habituated to it. It's there, but it's not an issue in my life.

Mr. Porter. It's there, as in Mr. Purjes' case, 24 hours a day, always?

Dr. Reich. Absolutely. I can always call it up and listen to it.

Mr. Porter. As I assume you know, we had William Shatner

here last year who talked about his tinnitus and what it meant in his life and his career. We consider it, obviously, a very serious matter that affects a lot of people in our country, millions and millions of people, and I think NIDCD takes it very seriously as well and is doing everything it can to put it at a high priority. We certainly will continue to press them on that.

We'll do our best to get the funds that they need. You heard sermonette number one or two earlier; we ask you to take that to heart. We'll do our best to put this at a high priority.

Thank you for testifying.

Dr. Reich. We very much appreciate your help. We know that you have been doing it, and thank you very much.

Mr. Porter. Thank you.

Mr. Purjes. Thank you.

Mr. Porter. Thank you, Mr. Purjes.

[The prepared statement of Gloria E. Reich and Dan Purjes follows:]

[Pages 1444 - 1450--The official Committee record contains additional material here.]

Tuesday, February 3, 1998.

WITNESS

DR. TALMADGE E. KING, JR., AMERICAN LUNG ASSOCIATION/AMERICAN THORACIC SOCIETY

Mr. Porter. Our next witness is Talmadge E. King, Jr., M.D., F.A.C.P, F.C.C.P., President of the American Thoracic Society and Chief, Medical Services, San Francisco General Hospital, testifying on behalf of the American Lung Association and the American Thoracic Society.

Dr. King.

Dr. King. Chairman Porter, I want to thank you for your leadership in supporting biomedical research. Without your leadership and the strong bipartisan support of this committee, many of the recent advances would not have been possible.

I am here on behalf of the American Lung Association and the American Thoracic Society to speak about the importance of biomedical research in public health programs. This year marks the 50th anniversary of the National Heart, Lung, and Blood Institute. The NHLBI has been steward to phenomenal advances in research and public health. We are pleased by this progress, but note that more work needs to be done. We would like to highlight two areas of concern regarding the fiscal year 1999 budget, and two threats to public health that we need to address.

The first note of caution is with the Administration's fiscal year 1999 budget proposal. While encouraged with the investment in research in public health programs, we are concerned that much of the Administration's budget is predicated on revenues from the tobacco deal. Enactment of the tobacco deal is neither imminent, nor is it necessarily in the

best interests of America. I strongly urge Congress and the Administration to make funding decisions based on the normal appropriations process.

The second concern is with NIH's management budget. For the past two years NIH's management budget has gotten smaller, while the programs have gotten bigger. To be good stewards, NIH will need appropriate resources to manage their growing research portfolio. We encourage the committee to be mindful of this when providing funds for NIH.

Mr. Chairman, although we are making progress in prevention and cures of many lung diseases, I want to focus my comments on two diseases--one new public threat, and one old.

The new public threat is asthma. Asthma is on the rise. An estimated 14.6 million Americans have asthma. Since 1984, the prevalence of childhood asthma has risen 72 percent. Asthma is expensive. Currently, asthma costs the U.S. over \$12 billion a year. Asthma kills; in 1994, 5,487 children died as a result of an acute asthma attack. That is over a 100 percent increase from 1979. A disproportionate share of these deaths were in African American families, with an age-adjusted rate three times higher than that of whites.

Research is bringing answers, and with answers come hope for new treatments and cures for asthma. Within the foreseeable future we expect researchers to fully describe the unique combination of genetic and environmental factors that can successfully address the prevention and cure of asthma. To get to a cure will require a continued commitment to funding asthma research at NIH.

Asthma also requires a public health response. Supporting asthma surveillance, reducing exposure to environmental asthma triggers, and patient education are needed to control asthma. CDC must play a role in providing the public health response to asthma. This will likewise require a funding commitment.

The old disease is tuberculosis. Tuberculosis has been with us literally since the dawn of man. Although tuberculosis is a preventable and curable disease, it persists as a health care problem in the United States and globally. Worldwide, there are over 7.5 million new cases of active tuberculosis and 3 million deaths annually. The newest twist on this old disease is the development of multi-drug resistant strains, or MDR-TB. In the United States, some strains of MDR-TB are resistant to as many as seven drugs. Recent investment in domestic TB control programs are beginning to pay off. While the data is still preliminary, we expect the CDC will announce a fifth straight year of decline in domestic TB rates.

The good news is a direct result of efforts by CDC and public health officials. It is important to continue this area of support throughout the period necessary to establish control of TB.

Progress is also being made globally. In fiscal year 1998, the Foreign Operations Appropriations Subcommittee provided USAID with funds for international TB control. To ensure appropriate coordination between U.S. domestic TB control, research, and international efforts, we strongly encourage CDC, NIH, and USAID to enter a formal interagency cooperative agreement regarding U.S. TB control activities.

We also recommend that USAID, in conjunction with CDC, NIH,

the World Health Organization, and voluntary professional organizations, develop an international plan to eliminate TB.

Mr. Chairman, thanks largely to the generous support of this committee, the research and public health communities continue to make advances against lung disease. We urge this committee to continue to supply us with the tools that we need to achieve a world free of lung disease.

Thank you for this opportunity to testify and for your ongoing support.

Mr. Porter. Dr. King, thank you for your testimony. I have to say that I agree with you, that it's very unlikely that we're going to have--and not a desirable thing to have--a tobacco deal that allows the industry to escape liability for damage already caused. I don't think there's going to be any such deal this year, and a lot of the spending in the President's budget, of course, is supported by that revenue source and others that I believe will not materialize. That means it's going to be much tougher for us to get the kind of allocation that we need to do the things that we put at a high priority.

I did hear you very clearly about the management at NIH. When NIH was provided a substantial increase in a budgetary environment in 1995 for fiscal year 1996, that was very much against what was happening in almost every other line item in our budget. We felt that NIH had to take the same burden of restraints on management costs as every other agency under our jurisdiction. We recognize that that has had a pretty heavy bit at NIH in terms of management. They've managed to deal with it quite well, but it is still a great difficulty.

But we will take into account your concern in that area, and we appreciate your expressing it to us.

Asthma and TB, obviously, are very serious diseases. My sister suffers from asthma, so I know a bit about it firsthand. We will do the best that we possibly can to provide the funds that are needed to address these diseases of the lungs that affect so many Americans.

Thank you for testifying.

Dr. King. Thank you.

[The prepared statement of Talmadge King, Jr., M.D., follows:]

[Pages 1454 - 1463--The official Committee record contains additional material here.]

Mr. Porter. You all heard the series of bells that have gone off. What it is is a series of votes on the House floor. I don't know how many votes are involved, at least two. What we are going to do is take one more witness, and then we're going to have to take a recess. I hope that the members can stay. I will come back as quickly as I possibly can and resume the hearing and stay until we complete our morning panel, but obviously it's going to set us back at least 25 minutes, maybe longer. I regret that. This is the first vote that we've had, but there's nothing that we can do about it.

Tuesday, February 3, 1998.

WITNESS

B. R. ``PETE'' KENNEMER, NATIONAL COUNCIL FOR COMMUNITY BEHAVIORAL HEALTHCARE

Mr. Porter. B.R. ``Pete'' Kennemer, Chairman, Board of Directors of the National Council for Community Behavioral Healthcare, and Executive Director, Western Arkansas Counseling and Guidance Center, testifying on behalf of the National Council for Community Behavioral Healthcare.

Mr. Kennemer, you're not going to get your testimony in before I'm going to have to leave, unfortunately. I thought we were a little bit ahead of the second bell but obviously we're not. If you start, I would have to leave in the middle of it, so I'm afraid that this is probably the time for me to declare the subcommittee in recess. We'll get back as quickly as we can.

We stand in recess until the end of this series of votes.
[Recess.]

Mr. Porter. Mr. Kennemer, welcome.

Mr. Kennemer. Thank you, Mr. Chairman.

My name is Pete Kennemer, and I am the Chairman of the National Council for Community Behavioral Healthcare, or NCCBH. Thank you for the opportunity to testify before you today concerning the need for the Federal Government to make an increased investment in the provision of community-based mental health and addiction services. Specifically, we are asking for an increase of \$80 million for the Community Mental Health Performance Partnership Block Grant (Mental Health PPG) which has been level funded at \$275 million for the last four years. We are also asking for increases of \$10 million in the Projects for Assistance in Transition from Homelessness (PATH) and \$200 million for the Substance Abuse Performance Partnership Block Grant.

NCCBH, organized in 1970, is a national trade association representing community behavioral healthcare through its diverse membership of nearly 800 community-based behavioral health provider organizations (community mental health centers), including state and regional associations of providers, networks of providers, and public authorities (State, county and local) which are responsible for the delivery of behavioral healthcare. NCCBH members comprise the spectrum of community behavioral healthcare from inpatient care and intensive outpatient treatment, to addiction treatment, residential programs, and funding of services. In many areas, our members are the gateway to accessing the public health system through both inpatient and ambulatory systems of care.

One of NCCBH's members is my own organization, the Western Arkansas Counseling and Guidance Center (WACGC), located in Fort Smith, Arkansas. It is one of 15 community mental health centers (CMHCs) in Arkansas and it is similar to the more than 600 CMHCs throughout the United States which provide services to those with mental illness and addiction disorders.

WACGC's founding mission in 1960 was to provide affordable psychological services to the citizens of Sebastian and

Crawford Counties in western Arkansas. Today, WACGC provides a wide range of coordinated behavioral healthcare services in its 15 locations throughout the six counties it now serves. We provide a comprehensive network of quality behavioral healthcare services to help prevent mental illness and treat the emotionally disturbed. Our programs are designed to be consumer sensitive, outcome oriented, and cost effective.

Like other community mental health centers across the country, WACGC provides a continuum of services through its network of 15 treatment locations. Services provided include: outpatient care, acute care, individual, group and family therapy, medication management, testing, community support, psychosocial rehabilitation, residential services, vocational and educational services, supported employment, and referrals to primary care physicians, external programs and agencies.

As President and CEO of WACGC, I know first-hand of the great need for services funded through the Community Mental Health Performance Partnership Grant (formerly known as the Community Mental Health Block Grant). In fiscal year 1997, my home State of Arkansas received \$2,232,840 through the Mental Health PPG and \$300,000 through the PATH program. Last year, WACGC received \$224,585 of those Mental Health PPG funds (which accounts for 3.5 percent of our \$6.543 million budget) with out about \$88,000 of that being used for children's programs.

Although the block grant represents a relatively small portion of program spending for my organization, it provides stability for our center--and others like it--which require a reliable source of funding to ensure continuity of care for our clients. Block Grant funds are often used to fund services where gaps may exist in programs or they act as seed money for new programs offering innovative services. However, in some States it provides up to 39.5 percent of the community mental health services budget--a significant base for stability.

An example of how WACGC used Mental Health PPG funds during the last year is a nine-year old child, his mother and two brothers who moved into our service area from another State. The boy, ``Brian,`` not his real name, has a history of multiple hospitalizations and special education placements due to behavior problems which include fire setting, physical aggressiveness toward other children and teachers, and poor academic performance.

Through case management and our juvenile services program, partially funded by the Mental Health PPG, WACGC was able to coordinate treatment for Brian and his whole family. Transportation, child care and temporary food assistance were found through fee community resources for Brian's hard-working mother who held down two jobs. Individual and family therapy was successful in teaching effective parenting skills, finding an after-school program, teaching Brian coping skills and determining better medication levels for him.

After several months, Brian's behavior improved dramatically. He became less aggressive, stopped playing with fire, running away from home, and hitting his brothers. Peer relations and frustration tolerance improved, as did task completion and eventually his own self-confidence. His mother also benefitted by learning to take charge of her destiny. She is now better equipped to identify problems, seek help, and is

more skilled and setting limits with all of her children. She has since bought a car and is independently going to a community college. Her family is functioning at a higher level, consuming fewer services and is in a position to make positive contributions to their community.

As you can see, services provided through the Mental Health PPG not only improve the lives of those treated, but have the potential to improve the quality of life for entire communities. By providing critical care in a coordinated, timely manner, we are more likely to avoid the long-term costs of more serious health and safety problems which are the results of an over-extended system of care.

Over the last 30 years, a growing body of evidence has demonstrated that most people with mental illnesses can be treated more efficiently and more cost-effectively in community settings than in traditional psychiatric hospitals. However, funding to organizations which provide these services through the Mental Health PPG have been left out in the cold.

In 1993, the first year that community mental health spending by the States surpassed State spending at psychiatric hospitals, the Mental Health PPG received \$300.1 million on Federal appropriations. Since that time, its annual funding was reduced to \$275.4 million for fiscal 1995 through 1998. If inflation is taken into account, funding has actually decreased by more than \$56 million per annum, despite the fact that the demand for community based services has significantly increased since that time.

Adding to the pressures of an already under-funded program, at least 13 States have closed an additional 21 State hospitals and six more States are planning to close eight more hospitals over the next two years, with four more States planning to merge two or more hospitals.

Beginning in fiscal year 1998, many State mental health agencies face additional extraordinary and unanticipated new budgetary pressures as a result of the Balanced Budget Act of 1997. The Act included restrictions on the use by States of Medicaid Disproportionate Share (DSH) to support State psychiatric hospitals and other mental health facilities.

Because many States included mental health DSH as a revenue in their general revenue funds, we believe that the withdrawal of DSH funds will have a negative effect on community mental health services as well as on State-supported psychiatric hospitals. The National Association of State Mental Health Program Directors (NASMHPD) estimates that the new DSH restrictions will result in a loss to the public mental health system of \$116 million in fiscal year 1999 and \$1.5 billion over the five year period 1998-2002.

Another threatening drain on overall State mental health budgets is the recent Supreme Court decision in *Kansas v. Hendricks* which opens the door to the civil commitment to State psychiatric hospitals of thousands of sexually violent criminal offenders, even if they do not have a diagnosable mental illness. At least 14 States currently have some form of law providing for the civil commitment of dangerous sex offenders and another 41 States submitted amicus curiae briefs in support of the Kansas law. Many of those States are expected to adopt similar laws within the next year.

Even further, a number of other factors which have led to dramatic changes to our Nation's public mental health system in the last decade can only exacerbate the problem of under-funding: the number of inpatient hospital beds has decreased; a growing number of States have privatized their public mental health system through Medicaid managed care for persons with severe mental illness; and eligibility rules for Supplemental Security Income (SSI) have had great impact on both adults and children. All these changes have compounded the pressure on the already strained local and State public mental health systems.

Now, more than ever, Federal investment in community-based care is needed to provide the most essential services to our most vulnerable populations. Recent estimates show that the \$275.4 million in Federal funds now appropriated to the Mental Health PPG is an increasingly critical source of funding for State and local mental health departments. Moreover, these dollars are being asked to fund a wider and more diverse array of community-based services.

In order to provide the services which are so essential to our communities and to keep up with the overwhelming demand for those services, my organization's programs and the others like it across the country need an increase in Federal funding to the Mental Health PPG and the PATH programs.

The PATH formula grant program, which helps States provide flexible, community-based services to persons who are homeless and mentally ill or who have a dual diagnosis of mental illness and substance abuse, are often the only monies available to communities to support the three levels of service necessary for success with homeless people who have serious mental illnesses, outreach to those who are not being served, engagement of the individuals in treatment services, and transition of consumers to mainstream mental health treatment, housing and support services.

A 1994 study by the National Association of State Mental Health Program Directors (NASMHPD) documented that roughly 127,231 homeless persons with mental illness were being served by PATH services. This is far below the most conservative estimation of the number in need.

An increase in Federal appropriations are necessary in fiscal year 1999 to achieve four purposes: one, health care coordination, particularly for services related to HIV/AIDS, tuberculosis, hepatitis, and other communicable diseases and dental care; two, training of persons to work with people with a mental illness/substance abuse dual diagnosis; three, housing support services; and four, increased capacity.

Although NCCBH and its member organizations were pleased to learn that the President's Balanced Budget Recommendations for fiscal year 1999 include a funding increase of \$200 million for the Substance Abuse Performance Partnership Block Grant, we were terribly disappointed to see that the recommendation has left funding for the Mental Health PPG at 1995 levels and the PATH program at 1998 levels.

On behalf of NCCBH, I respectfully request that this subcommittee recommend an increase in funding for the Mental Health PPG for fiscal year 1999 by at least \$80 million, an increase in funding for the PATH program by at least \$10 million and an increase of \$200 million for the Substance Abuse

Performance Partnership Block Grant.

As a final note, NCCBH would like to recognize SAMHSA's leadership in convening a consortium of mental health consumer and professional groups like ours in helping to raise awareness about mental illness and to dispel the negative perceptions and stigma surrounding behavioral disorders. On Saturday, May 2, 1998, NCCBH is co-sponsoring a one-mile walk through Washington, D.C., to educate and alert people that appropriate mental health services can prevent minor behavioral health disorders from compounding and that there is the promise of recovery for many people who have serious mental illnesses. You will be hearing more about this effort in the coming months.

Once again, I thank you for this opportunity to present our requests to your subcommittee concerning fiscal year 1999 appropriations. I would be happy to answer any questions you may have or provide further information at your request.

[The prepared statement of B.R. Pete Kennemer follows:]

[Pages 1469 - 1478--The official Committee record contains additional material here.]

Mr. Porter. Mr. Kennemer, we appreciate your good testimony. You can be assured that the subcommittee will give it every consideration.

Wednesday, February 4, 1998.

WITNESS

ROBERT A. WEINBERG, THE JOINT STEERING COMMITTEE FOR PUBLIC POLICY

Mr. Porter. Our next witness is Dr. Robert A. Weinberg, Professor of Biology at the Whitehead Institute for Biomedical Research at the Massachusetts Institute of Technology.

Dr. Weinberg, welcome, and we look forward to your testimony.

Dr. Weinberg. Thank you, Mr. Chairman, and members of the subcommittee. I am Robert Weinberg, and I am here today as representative of the Joint Steering Committee for Public Policy and 25,000 of my colleagues in the basic biomedical research community, particularly my own Society, the American Society for Cell Biology. I thank you and your colleagues for the opportunity to present my views to you today.

My own research is carried out at the Whitehead Institute for Biomedical Research, closely affiliated with MIT in Cambridge, Massachusetts. For the past three decades, I have been involved in research on the molecules inside the human cell; much of my research focuses on the molecular and genetic origins of human cancer. Last year, I was deeply honored to be presented with the National Medal of Science by President Clinton.

I focus today on cancer research, using it as an example. It is only one of a dozen major human diseases that are now under successful attack by the research community. Like the others, autoimmune diseases, Alzheimer's, genetic and metabolic

diseases and heart disease, cancer is finally revealing its secrets. The fallout from the discovery 40 years ago of the genetic code has descended on us, and now affects, indeed revolutionizes, our understanding of virtually every human disease. Two centuries from now, those looking back will say that we lived during a time of major scientific revolution.

Still, I don't want to talk today about a century or two of future progress. My vision is limited to the next decade, or at most two. That time line is dictated by the delay between initial scientific discovery at the lab bench, and the resulting impact of that discovery on patient treatment in the clinic. In my own career, as an example, a discovery made in my lab in 1981 has only this year resulted in a new, and apparently highly successful treatment for breast cancer. By the same token, the basic research findings that are now in hand will only have their full impact on medical practice sometime over the next decade.

I would like to generalize from my own personal experience to that of the research community as a whole. Over the past two decades, my colleagues and I have generated a rich storehouse of information on how cancer begins. Over the next decade, we will draw on this information to develop what I believe will be a number of dramatic new cures for cancers. These advances will flow directly from the rich scientific knowledge base that we have assembled since 1980, most of it deriving from research supported by our Government and enabled by this subcommittee.

We now have a clear vision of how to kill tumor cells by forcing them to commit suicide, or by strangling their blood supply, or by crippling their ability to multiply without limit. We have the cells use to stoke their own growth; we have uncovered the molecular clock that prevents normal cells from growing without limit, and in broken form, allows cancer cells to multiply until they become lethal threats. These discoveries are just now being converted into treatments that will be effective in the treatment of people with cancer.

I want to talk today about how all this can happen, or perhaps, how we may forego the opportunity for it to happen. In spite of the stunning opportunities that I've just mentioned, we are not prepared to take advantage of this rich knowledge bank that we have accumulated. Indeed we have now a data base to convert this basic research into a variety of cures over the next several decades.

Ironically, at a time when we're poised so beautifully to take advantage of all this basic research information we've gained over this period of time, one thing is not in place, and we're not prepared in the way we should be. Ten, 15, 20 years ago, the young, the smartest and the best of the young people were pounding down the doors of our laboratories trying to get in. And that's changed now.

Sadly, over the last 10 years, the best and the brightest are no longer flocking to do basic research. The reason being that careers in basic biomedical research are no longer attractive, not because the problems are not compelling, not because there aren't exciting opportunities to make really big advances, but simply because the career of being a researcher has become extraordinarily unattractive, for the simple reason that the career path is strewn with too many obstacles. The

university departments are having difficulties to support the training grants to support the training of Ph.D. students. Laboratories have become outmoded.

The biggest obstacle is the fact that research funding has become so tight that most young people see correctly at present that the chances of their launching a career and having a career after having gone through eight or ten years of post-undergraduate research are remote, 20 percent probability.

Therefore, the best and the brightest are becoming lawyers, some are becoming clinicians, some are becoming bond salesmen on Wall Street. They're making good livings, but they aren't staffing the laboratories when we're going to desperately need them, 5, 10, 15, 20 years from now. We've not been able to bring up a new generation of young researchers to take advantage of the enormous opportunities that have been generated by the last two decades of research, much of which, the great bulk of which was funded through appropriations of this subcommittee.

So I want to make a plea that we begin to recognize the central role played by young people in the age range between 20 and 40 years. They are the people who drive research forward. Yet they are a dwindling research. The quality of them has gone down because of the reasons I've just mentioned.

One other problem, to close, has come to the fore, in the last five years. The ultimate development of cures for a variety of these diseases is going to depend on what is known as clinical research. Clinical research which is carried out by young physicians who are trained both in laboratory science and in the art of medicine.

These young people are skilled in understanding basic biomedical research findings and developing new kinds of treatments and yet, clinical research is suffering grievously over the last five years, largely because of the fact that the restructuring of health care has really pulled the carpet from under those who in the past have been able to divert clinical revenues to support research.

Therefore, even more than basic biomedical research, which I represent, clinical research in this country is under enormous threat, because the funds that have traditionally made it possible have now in many areas virtually evaporated because of managed health care.

So I would like to put in a plea as well for that area. It's not my own bailiwick, but an area that is going to need attendance to over the next years if indeed we are going to take advantage of these research opportunities to develop new kinds of treatments for a wide variety of diseases. The information is there, but our ability to effect cures is now under threat for the reasons I've just described.

Thank you for the opportunity to present these views, sir.

[The prepared statement of Robert A. Weinberg follows:]

[Pages 1482 - 1489--The official Committee record contains additional material here.]

Mr. Porter. Dr. Weinberg, I think you've presented very

compelling testimony and put your finger on things that we had better be worrying about and addressing and solving. The training grants and infrastructure that you mentioned, obviously, we can address directly.

The tightness of research funding, it's fascinating that we have, if you look historically at NIH, the rate of increase over its whole 50 year history has been at about 3 percent real terms. We have been doing actually a little bit better than that in the last couple of years with low inflation.

Mr. Weinberg. Indeed.

Mr. Porter. But you're exactly right, that the number of grants that can be funded as a percentage of those that are competed and determined to be worthy of funding has gone down. The chance of getting a proposal funded is less, even in the face of increasing amounts of money.

That's because there is so much good research that is available if only we had the funds to do it. What that tells me, and I think a lot of people, is that we have to make a renewed commitment to really increase funding for NIH and basic research and not to look at the historic 3 percent real terms, but see if we can actually double the funding over the next five years, and attract the kind of young people and the kind of talent that is there, but is going elsewhere, as you point out, very forcefully.

So that's to me a very high priority. Unfortunately, I don't have direct jurisdiction over it, but I'll do everything I possibly can to influence our Budget Committee to take this and run with it.

I said yesterday, and I'll say it again today, I think the chances of doing that this year are probably not very strong. We can lay a foundation this year and get into peoples' minds that this is important, and what it means to our country, and what it means in terms of lost opportunity, if we don't do it.

I'm doing everything I can, and I think other members of the subcommittee are as well, to do exactly that. I know you're doing that, and members of the research community and the patient advocacy groups and the pharmaceutical and biotech industries and the like, all I think are raising consciousness of the American people about this subject and why it ought to be a priority for the country.

On the clinical research side, again, you're exactly right, the revolution that's gone on in the last few years in how we deliver health care has led managed care not to contract with our academic medical centers, and they are in tough shape in terms of funds to carry on their very important work. We are going to have to, again, it's not my jurisdiction, it's the jurisdiction of the authorizing committees, they're going to have to do something to address this problem and do it forcefully.

I can do some. I can direct some resources there. But you really need a whole new way of providing a funding base so that clinical research can continue in the way it has in the past. If we don't do that, I think we're all going to be in real trouble.

So your testimony is excellent, you put your finger exactly on the same problems I think we have to face. All I can say is that we're putting these on a high priority and doing

everything possible to address them.

We thank you for coming here to testify.

Mr. Weinberg. Mr. Chairman, we have to build for the next generation. We need the young people.

Mr. Porter. Absolutely. Can I ask you one question before you leave? When did MIT begin to do biomedical research?

Mr. Weinberg. Seriously in the late 1950s. We now have one of the best, at the risk of sounding self-aggrandizing, one of the best departments in the country. But we started up really almost exactly 40 years ago.

Mr. Porter. Right after I left. I was a student once at MIT.

Mr. Weinberg. I didn't know that. A Tech man.

Mr. Porter. Yes. Absolutely.

Thank you, sir.

Wednesday, February 4, 1998.

WITNESS

JOE MAUDERLY, LOVELACE RESPIRATORY RESEARCH INSTITUTE

Mr. Porter. Joe Mauderly, Director of External Affairs, Lovelace Respiratory Research Institute, testifying in behalf of the Institute. Dr. Mauderly.

Dr. Mauderly. Thank you, Mr. Chairman. I appreciate the opportunity to describe to you a new initiative that has special significance for the country. I'm here to propose that the Departments of Health and Human Services and Labor participate in an interagency effort called the National Environmental Respiratory Center, which is aimed at understanding the health risks of combined exposures to multiple or mixed pollutants.

I don't need to recount the importance of respiratory disease to the Nation. My colleague, Dr. King, whom I know well, put that eloquently earlier. It is a very serious problem.

We also need to remember that occupational lung disease is a part of that problem, in fact, it's the number one work-related illness in terms of its severity, frequency and preventability, if you will.

Now, the relationship between air contaminants, be they environmental or occupational, and respiratory disease, is really not very well understood, despite the publicity and the work that's been done. Air pollutants are known to aggravate respiratory illness, and that's easy to understand.

What we don't understand very well at all is their potential contribution to causing respiratory illness. There is evidence from our lab and others that inhaled contaminants can contribute to causation of diseases like asthma and other respiratory illness.

One part of this problem is that it's so difficult to understand the relative roles of different materials that people breathe. Different pollutants can have the same effect, some pollutants can enhance the effect of others. It's largely unknown but very plausible and generally agreed by the scientific community that mixtures of pollutants, each at their

individually acceptable level, might have an unexpected or unacceptable aggregate risk that we don't really understand at all.

Present environmental and work place air quality regulations address pollutants one at a time. That's a problem, because that's not true. Nobody ever breathes just one pollutant at a time. And that's intuitively understandable.

When you think about it, under our present strategy, it would be considered that an individual breathing all environmental and occupational pollutants, all at the same time, each within their maximum allowable concentration, would have no greater health risk than if they were breathing one of them. Yet that doesn't really pass the laugh test.

The real issue is not the regulation or their legislative basis. We know that can be changed. The real issue is that we don't have an understanding. There's a lack of research in the area of combined exposures to multiple inhaled materials.

Now, this kind of research is difficult. It takes some special capabilities. It's not incentivized by the alternate prioritization of single air pollutants that is prevalent in the research community driven by regulatory issues. The National Environmental Respiratory Center is a new interagency, interdisciplinary initiative that's designed to catalyze a new body of research to address this issue.

The effort was begun this year with start-up funding in the EPA appropriation, but no single agency has the responsibility for this issue. The Center is established at the Lovelace Respiratory Research Institute, which is an independent, non-profit research institute totally focused on respiratory disease, in part because Lovelace happens to be one of the organizations in the country that has substantial experience in combined exposure studies. It also manages a recently privatized Federally-owned facility that's ideal as serving as a physical location for this center.

The mission of the Center is to stimulate and facilitate and also participate in a national initiative that will be long range aimed at understanding the health effects of mixtures of pollutants in the environment and the work place. The Center will conduct research, it will be guided by a competitive peer review process. That will be an intramural program. It has no intention of being another granting agency.

The Center will maintain information resources available to Congress, agencies, researchers and the public. The Center will play an important role in assisting agencies and facilitating communication, planning and coordination to define this issue and define research approaches that will be needed to solve it. Especially in bringing communication to occur between health scientists and atmospheric scientists, which do not talk to each other nearly as much as they need to. And will make specialized facilities available.

Now, it's very appropriate for the Department of Health and Human Services and Labor to participate in the Center. NIH, NIHS, NCI, has recognized this. It's especially appropriate for NIOSH, because of occupational concerns for mixed exposures are recognized in its strategic plan. But there's very little research support actually in this area. It's a very complicated problem.

So Mr. Chairman, we seek your committee's help in encouraging the agencies under your purview to recognize the issue and to participate in moving this initiative forward.

Thank you for the opportunity to testify.

[The prepared statement of Joe Mauderly follows:]

[Pages 1494 - 1504--The official Committee record contains additional material here.]

Mr. Porter. Dr. Mauderly, where is Lovelace Institute?

Dr. Mauderly. It's in Albuquerque, New Mexico.

Mr. Porter. Albuquerque. When was it established?

Dr. Mauderly. Lovelace is an organization that goes back to the pre-World War II era. It developed a substantial research component as well as a health care activity in the post-war era.

Mr. Porter. I'm sorry, I meant the National Respiratory Health Center. When was that established?

Dr. Mauderly. The National Environmental Respiratory Center is being established as we speak. The initial funding was in this year's EPA appropriation. So it's a new initiative.

Mr. Porter. Was that initial funding in the EPA appropriation according to an authorization that was previously passed?

Dr. Mauderly. That was language that was put in the appropriation along with funding for a number of other centers and activities related to air pollution issues.

Mr. Porter. What I think I'm hearing, I just want to get the concept that you want us to encourage certain agencies under the jurisdiction of these three Departments and under the jurisdiction of the subcommittee, to look into support for the work of the Center.

Dr. Mauderly. That's right, the work of the Center and related support. I'm asking and encouraging your awareness of the issue, the awareness of the agencies of the issue, in general, as well as specific support for the Center. We know that 20 years from now, we can't be addressing either work place or environmental air contaminants one at a time in isolation as we have been for years. This is an initiative to move us forward into designing another paradigm.

Mr. Porter. Well, we appreciate very much your testimony today. You've educated me on the existence of the Center and what Lovelace does, and I appreciate that very much.

Dr. Mauderly. Thank you.

Mr. Porter. We'll do our best.

Wednesday, February 4, 1998.

WITNESS

KENNETH G. MCINERNEY, COMMITTEE FOR EDUCATION FUNDING

Mr. Porter. Kenneth G. McInerney, President, Committee for Education Funding, testifying in behalf of the Committee. Mr. McInerney.

Mr. McInerney. Good morning, Mr. Chairman. I am Ken McInerney.

Mr. Porter. Unfortunately, it's afternoon.

Mr. McInerney. Good afternoon. [Laughter.]

I am Ken McInerney, of the National Association of Student Financial Aid Administrators. I'm here today as the President of the Committee for Education Funding, which is a non-partisan coalition founded in 1969 with the goal of achieving adequate Federal financial support for our Nation's educational system.

The Committee is the largest coalition of educational associations in existence, with over 90 members, whose interests range from preschool to adult and post-graduate education in both public and private systems.

Let me first begin, Mr. Chairman, by recognizing the outstanding efforts of you and members of your subcommittee in making education funding a priority during the last two fiscal years. We are particularly appreciative of the strong, bipartisan support education programs have enjoyed in this subcommittee. We look forward to helping you make this a tradition that reaches many years into the future.

During the past two years, Federal discretionary education spending has grown by \$7 billion, which has helped restore cuts enacted in the previous two fiscal years, and provided growth and investment in critical programs that expand educational opportunities for Americans in all stages of life. These increases, however, must be considered in a larger context. Over the past 15 years, deficit reduction efforts forced cuts in Federal education funding, both as a share of the total Federal budget and as a share of the total support for education.

America now faces a host of new challenges to our educational systems, including rising enrollments, more students with special needs, increasing teacher shortages, overcrowded, unsafe and outdated facilities, rapidly advancing technology and continued access to post-secondary education for low income students.

Mr. Chairman, as we begin the debate on fiscal year 1999 funding, which I note will affect the 1999-2000 school year for many programs, the Committee for Education Funding asks that you and your subcommittee, to carry forward your momentum from the previous two fiscal years, and make a comparable investment in America's children, youth and adults in fiscal year 1999.

The United States today has a unique opportunity and a strong incentive to invest in the future. The American economy has never known such sustained growth. We have never been so free from external threat or domestic crisis. We enjoy the highest standard of living in the world. We have slashed Federal deficits and can anticipate years of surpluses, according to the Congressional Budget Office.

If we are to maintain and enhance these accomplishments into the 21st century, the Federal Government must continue to provide and promote activities that ensure future economic vitality, personal security and expanded opportunity for all Americans. Investing in education now is the surest way to meet these goals.

As you know, America's system of education, from preschool through graduate education, has played an essential role in our

Nation's success. We must build on these successes and again make education a major part of America's strategic plan. We need substantial new Federal investment in education, not incremental increases, to meet these challenges.

Mr. Chairman, you should know that CEF, the Committee for Education Funding, supports the President's efforts to open up new revenue streams for education through tax expenditures and mandatory spending. We must reiterate, however, that it is vital to maintain and enhance support for the core proven education programs within the jurisdiction of this subcommittee, which have been held back, not from poor design, but from inadequate funding.

In addition, we urge you to provide adequate funding for those important education programs proposed for reductions or level funding in President Clinton's fiscal year 1999 proposal. We also note that the budget agreement reached last year continues spending constraints on discretionary spending for the next several years. We recognize the pressure that this creates by pitting health research programs and education programs in competition.

We are ready to continue working with your subcommittee and with the health research community, with whom we have worked in recent years, to secure a budget allocation and new resources adequate to accommodate significant investment in both of these important areas, which may include re-examining the current statutory appropriations caps.

In addition to creating a supportive climate for education, Mr. Chairman, we must understand that education is a pipeline. What we do for the youngest in our society has long term effects on test scores, graduation rates and success beyond school. Elementary education must provide a solid academic foundation to prepare for secondary school. Middle schools and high schools must challenge more students to meet higher standards, so they are successful in post-secondary education. Vocational technical community colleges and universities must assure students are prepared for lifelong learning on the job.

We can sustain our success by preparing for the future. The Committee for Education Funding urges Congress and the Administration to prepare for a future that is brighter than ever before, and we thank you for the opportunity to testify today.

[The prepared statement of Kenneth McInerney follows:]

[Pages 1508 - 1514--The official Committee record contains additional material here.]

Mr. Porter. Mr. McInerney, I realize I'm keeping all the witnesses a long time, and I'll try to be brief. The sermonette that I gave earlier, often I give it in respect to someone who is testifying regarding biomedical research, because many of our witnesses are witnesses who testify on that broad subject.

But it is meant for everyone. We have to get the allocations that we need to provide funding for all of the priorities under our jurisdiction. The help of people concerned about all of those priorities is needed to assure that the

allocation is forthcoming.

I don't want people to think that I'm limiting it at all. Obviously we have, I think, under our portfolio, very many very important programs to help particularly people at risk. Kids are always the most important, obviously, and education funding, as you say, is really the future of this country. With that we agree very much.

So any help you can give us on the budgetary side will be reflected in our looking at these education programs in a much more favorable light with more resources available.

Mr. McInerney. Thank you, Mr. Chairman.

Mr. Porter. Sermonette number three. Thank you, Mr. McInerney.

Wednesday, February 4, 1998.

WITNESS

JAMES T. CORDY, NATIONAL PARKINSON FOUNDATION, INC.

Mr. Porter. James T. Cordy, Chairman, The Parkinson Alliance, testifying in behalf of the National Parkinson Foundation, Inc.

Mr. Cordy.

Mr. Cordy. Thank you, Mr. Chairman.

You mentioned you have a new timing device. I brought a rather old one with me. If it holds together for five more minutes, I'll be happy.

Mr. Porter. It looks like it has a lot more than five minutes in it.

Mr. Cordy. Mr. Chairman, members of the Committee, my name is Jim Cordy, and I have Parkinson's disease. Formerly, I was an engineer in research and development in a specialty steel company. Parkinson's forced me onto disability three years ago.

Currently, I am President of the Pittsburgh chapter of the National Parkinson Foundation, a member of the board of directors of the National Parkinson Foundation in Miami, and the new leader of the Parkinson's Alliance. I'm also proud to say I'm part of that magnificent grass roots effort that saw passage of the Morris K. Udall Parkinson's Research and Education Act. I'm here today to give testimony in support of fully funding that authorization.

This hourglass serves several functions. Hopefully it will help me stay within my allotted time. It also is intended to convey to you that we who have Parkinson's are in a race against time. Just as the top chamber is depleted relentlessly grain after grain, so is my top chamber, my brain, losing brain cells which control movement day by day.

The Parkinson's Alliance is not another organization. Rather, it's a loosely organized overlay of the current organizations. It's the voice of the people with Parkinson's. Those people first want to say thank you, to you and your committee, for allowing the Udall bill to be amended to the appropriations bill. Obviously you appreciate the broad based bipartisan support this bill has.

This was demonstrated last year in the 95-3 roll call vote before the Senate and by the 255 cosponsors that we managed to

amass in the House.

The overwhelming majority of neuroscientists agree we are poised in the threshold of curing this sinister disease. This hourglass is an attention getter which I hope distinguishes my testimony at this busy hearing. Yet the promise of a near-term cure for Parkinson's disease is no gimmick. It's doable, and it's doable now.

As I speak, researchers from all over the world are assembling in a meeting in Arizona to discuss that promise. Let us provide them with the resources to make that promise a reality. Find a cure and then direct those resources at other diseases.

If we as a Nation don't find a cure or new effective treatment for these age-related diseases, when the baby boom ages, it's going to devastate any attempts we've made to date to balance the budget.

There are two other economic points which favor increased funding of Parkinson's disease research. Currently, NIH research funding is measured by dollars per person afflicted. It's simply not equitable. Second, Parkinson's is estimated to cost society \$25 billion a year. If this \$100 million a year investment in research leads to a cure, every dollar spent will save \$250. That's an ROI that any private industry would pass in a minute.

I'm here today to help give Parkinson's a human face. Parkinson's disease is a degenerative disease of the brain. As a result, my hands and legs sometimes shake and my body stiffens. I have witnessed these slowly but surely erode my physical abilities. I can no longer tie my tie, wash my hair or tuck in my shirt. I can't shuffle papers in my office, nor drive my car.

I have lost facial expression, a sense of smell, and I now have a monotone voice. I wouldn't be here today if that was the extent of my problem. Unfortunately, those are just previews of the horrors to come if we don't find a cure for this sinister disease.

What terrifies me is the real possibility that I could end up like Mo Udall, bedridden, unable to talk or move. I sometimes think I do not serve the Parkinson's community well when I come to Washington. For when my medications are working, I approach some degree of normalcy. Perhaps as I walk away from the table, some may think, he doesn't look so bad.

Those medications without which I wouldn't be able to function lose their effectiveness with time. They're beginning to, they're just happening to me now. I'm falling behind in my race against time.

The image I want to leave you is the image of the horror of Parkinson's. A woman from California wrote to tell me of the death of her mother, a former Olympic athlete who had Parkinson's. She described how this once athletic body had shriveled to 60 pounds and had assumed a constant fetal position for the last several years. That's the image of Parkinson's I want to leave with you, that and the promise of a cure.

Let me assure you that I'm not going to sit back and wait for my body to stop working. I'm determined to win this race, but I need your help.

Before closing, let me turn this hourglass over. The top chamber is replenished, just as a scientific breakthrough that cures Parkinson's will replenish my brain of the cells which control movement. Don't let time run out for me and the one million Americans who have Parkinson's. Not when the finish is in sight.

Thank you.

[The prepared statement of James Cordy follows:]

[Pages 1518 - 1523--The official Committee record contains additional material here.]

Mr. Porter. Mr. Cordy, that was five minutes, wasn't it.

Mr. Cordy. Four minutes and 56 seconds.

Mr. Porter. Perfect. [Laughter.]

I had the wonderful honor and pleasure of being able to serve part of my time in this body with Mo Udall. I often say I had a wonderful trip to Alaska with Mo Udall, best trip I ever took with anybody anywhere, in 1987, right about the time when the disease began to really slow him down.

I don't think there is a member of this body in memory who has more respect or friends and more people who care about him. In addition to Mo, you know we have two members of the House, two members of the Appropriations Committee, as a matter of fact, Joe Skeen of New Mexico and Joe McDade of Pennsylvania, both who have Parkinson's disease.

I can tell you without fear of contradiction at all that these two gentlemen, maybe particularly Joe, have just been absolutely the strongest advocates for getting research funding into Parkinson's that you can imagine. They would certainly tell you that out at NIH as well.

We put this at a very, very high priority. We understand the nature of this disease and how it affects people. We want to do everything we possibly can to provide the resources and science so we can get a breakthrough and prevent it from happening in the future. We're going to do our best for you, absolutely.

Thank you for coming here to testify.

Mr. Cordy. Thank you. Mr. Chairman, this advocacy effort has been a learning process for me. One of the learning processes was today, when I gained new respect for you, sir, as you sit here individually and listen to each and every one of these witnesses.

Thank you.

Mr. Porter. Thank you. Can we borrow your hourglass? That might be far more effective than our device here. [Laughter.]

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness]

Wednesday, February 4, 1998.

WITNESS

LAURIE FLYNN, NATIONAL ALLIANCE FOR THE MENTALLY ILL

Mr. Porter. Laurie Flynn, the Executive Director, National Alliance for the Mentally Ill, testifying in behalf of the Alliance.

Ms. Flynn.

Ms. Flynn. Thank you very much.

Good afternoon, Mr. Chairman. I want to say how pleased I am to have the opportunity to share some thoughts from NAMI members with you this afternoon.

NAMI is the Nation's largest grass roots organization representing people with severe mental illnesses and their families. We are 172,000 strong in over 1,100 communities in all 50 States.

As you well know, Mr. Chairman, research is vitally important to people with severe mental illness who live each day with devastating brain disorders such as schizophrenia, manic depressive illness, clinical depression and severe anxiety disorders. Scientific advances led by NIMH funded research is heralding today a new era of hope for persons who struggle with these illnesses. Treatment that's been made possible by new science is making a real difference in promoting independence and recovery for more and more individuals with these very difficult diseases.

In fact, my organization has been able to use some of the results of NIMH science to help communicate an important message that these are brain disorders, despite myth and ignorance, and that treatment is increasingly successful. The clear evidence from this science also helps us enormously in our battle to reduce the stigma that's often unfairly attached to a mental illness diagnosis.

Mr. Chairman, NAMI members across the country are deeply grateful to you and to members of your subcommittee on both sides of the aisle for your vigorous and sustained leadership in bringing record increases to the NIH budget. We are especially gratified to see and do applaud the President's recently announced budget proposing \$1.15 billion increase in the NIH overall appropriation, and a nearly \$60 million increase for the NIMH.

These increases will be, we think, a wonderful way to close the decade of the brain and will build on the remarkable advances we have seen in neuroscience during this decade.

While NAMI members enthusiastically support NIH and NIMH, we are urging that more attention be focused on the most severe and disabling illnesses. NAMI reviews the NIMH portfolio each year, and we continue to document a large share of the portfolio that is directed to broad behavioral and social science research that we think misses the importance of NIMH's historic mission focusing on severe mental illnesses as a public health priority.

We have had a very extensive and productive dialogue with leaders at the NIMH who have recognized a 10 percent drop in research on schizophrenia in the past year, and have further recognized they need to strengthen their focus on bipolar disorder.

Mr. Chairman, NAMI is not suggesting that Congress micromanage NIH or earmark funds. Rather, we are recommending

that new and additional resources that may become available focus strongly on the most severe and disabling illnesses.

NAMI believes research on these brain disorders has the greatest potential payoff for American taxpayers over the long run. Most importantly, we know that research on serious mental illness saves lives. My own daughter, Shannon, who was diagnosed with a severe mental illness, is one such example. Despite over 10 years of illness, Shannon today, thanks to research based treatment, graduated from Georgetown University, lives on her own in an apartment, holds a job. Last fall, in the realization of a long-held dream, she returned to graduate school.

We know that this kind of success is possible for many thousands more who are afflicted with some of the most mysterious illnesses known to humankind.

Finally, Mr. Chairman, with regard to the Substance Abuse and Mental Health Services Administration and the Center for Mental Health Services, NAMI wants to express disappointment that the President has once again proposed to freeze all funding for CMHS programs. As you've heard earlier, pressures on State and local mental health systems are growing by welfare reform efforts to put violent sexual predators in State mental institutions, Medicaid disproportionate share cuts, and most especially as you've heard, the growth of managed care in the public sector.

This intense pressure to conserve dollars is felt most acutely by people with serious mental illnesses. They and their families are too often forced into the public system because of inadequate and discriminatory private health insurance and public programs that trap them in a dependency based system. While we are as a Nation making progress on these issues, with the focus on parity legislation at the Federal and State level, the availability of new treatments and efforts to reduce stigma, more needs to be done.

One small step would be to urge greater effort by CMHS for initiatives that educate and support vulnerable consumers and their families in coping with systems change.

Thank you very much, Mr. Chairman, for this opportunity to testify. Thank you again for your compassion and for your leadership on these health issues.

[The prepared statement of Laurie Flynn follows:]

[Pages 1527 - 1532--The official Committee record contains additional material here.]

Mr. Porter. Ms. Flynn, thank you for your testimony. I say often, and I think this is very important, that if you talk to scientists at NIH, they would I think very quickly agree, we know a great deal about the rest of the body. We don't know nearly enough about the brain. This is where we must put resources, and put it at a high priority, because this is where our knowledge is the least.

I think often the public looks at the debates on the Floor of the House of Representatives and at hearings before committees as well, that that's where all the business of

Congress goes on. Actually, I had a very good discussion on the way over to the floor on the last vote with Sander Levin, a member from Michigan, whose wife works out at NIMH, about priorities in mental health research funding that parallels exactly what your testimony has been highlighting for us today.

Obviously, that helps me in working on the priorities and funding for the subcommittee as well. That's often the way legislation is addressed, member to member, that no one ever sees. It works well, along with the obvious input and education that we get in having the opportunity to hear from you and your fellow witnesses in hearings like this.

So thank you for coming to testify today, we appreciate it very, very much.

Ms. Flynn. Thank you very much, Mr. Chairman.

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Wednesday, February 4, 1998.

WITNESS

MARTIN STEVENS, PROSTATITIS FOUNDATION

Mr. Porter. Martin Stevens, Pilot for United Airlines, testifying in behalf of the Prostatitis Foundation.

Mr. Stevens. Good afternoon, Mr. Chairman.

Mr. Porter. Good afternoon.

Mr. Stevens. I can't tell you how many times I've flown over the Capitol and kind of wondered what was going on down there, and now I have a better appreciation.

Mr. Porter. I was probably in a number of the planes that you've flown.

Mr. Stevens. I am Martin Stevens, and I have chronic prostatitis. I was diagnosed with the disease at age 16, in 1959. About a year after recovering from a urinary tract infection, and well before I was sexually active.

At first, antibiotics relived my symptoms. However, episodes were recurring about every 18 months to two years. As I grew older, these episodes became more frequent and more intense.

I flew more than 100 missions as a pilot in Vietnam, and I remember on one mission wondering whether I was going to make it back to base or not because of the pain.

I would like to share with you what it's like to have chronic prostatitis. I wake up each and every morning with lower back pain. I have moderate pain when voiding and can never seem to void completely. This is why I have to make frequent visits to the bathroom during the day. That's, by the way, why I fly multi-engine airplanes, because they have bathrooms.

At night, it's the same thing. There is always a sense of great urgency when I have to void. I have spent many a day sitting in a hot bathtub in order to find relief from the pain deep within my pelvic area.

Most of the over-the-counter drugs provide just temporary relief. Prescription drugs would disqualify me from performing my job. Besides, most sufferers report getting hooked on these drugs just after a short time.

Even my marriage has been severely affected by this disease, because of the moderate to severe pain that accompanies intercourse.

Since my initial diagnosis, I have seen over 25 different urologists, spent thousands of dollars on drugs, doctor bills and traveling, not including the loss of work caused by incapacitation. I have sought medical care abroad, living for more than two months in a third world country where there were rumors of a possible cure.

While abroad, I met many Americans afflicted with prostatitis. They all had very similar stories regarding the progress of their disease. Especially regarding the treatment received in America.

Many of them were so upset that they held their personal physicians responsible for their condition. There is no standard of treatment for prostatitis. Most urologists give antibiotics without properly culturing the patient in order to determine the proper antibiotics to use. In time, like myself, most antibiotics become ineffective, and the disease just progresses.

The urological community is not only split on the causes of the disease, but also its management. That is why finding the cause of this disease is so important. The cure rate for American patients seeking help in the overseas community I visited was dismal, just as it is in the United States.

Additionally, my medical insurance company refused payment for any of the treatments or drugs I received overseas, because they considered it experimental. I returned home quite depressed to say the least. Psychologically, I've learned to cope with the ramifications of the disease, with the help of counseling.

To top this all off, my sons, Mark and Danny, were diagnosed with prostatitis at age 16 and 17, respectively. Their diagnosis was also made before they were sexually active. Dr. Talia Toth, a medical doctor and fertilization specialist, and director of the McCloud Laboratory in New York City, first brought the possible familial aspect of the disease to my attention. He was of the opinion that prostatitis was a bacterial or viral infection that could be carried into the egg by the sperm during the fertilization process and for unknown reasons not express itself until adolescence, when the prostate begins its growing.

Clearly, more research needs to be done to get the answers we need and understand and treat the disease. The internet news groups are full of horror stories from fellow sufferers, desperately seeking advice regarding what doctors to see, what medicines or therapies to try to be cured or find some relief from this disease.

Many of these victims have gone to the professional journals, as I have, and gained an enormous amount of information on this subject. In fact, many prostatitis patients now know as much or more than the doctors who attend them.

Many years ago, it was thought that ulcers were caused by psychological problems. Today, we know that the bacteria helicobacter pylori is the culprit in many of the cases. Moreover, this bacterium has now been implicated in adenyl carcinoma, or cancer of the g.i. tract. In other words, a

bacterium caused the development of a cancer.

It would be less than a coincidence if our researchers were to find that same mechanism at work, a bacterial infection at play in the development of prostate cancer. Is it possible that underlying each and every case of prostate cancer there is a case of prostatitis? Silent or otherwise.

Can you imagine the ramifications of such a discovery? There's only one way to find this answer and in addition stop the needless suffering and loss of life that at some time or other will impact nearly two-thirds of American males in America. That way is through research, research and more research until we find the answers and create the cure.

On behalf of those men whose lives have been adversely affected by diseases of the prostate, I want to sincerely thank you and the members of your committee for your past support of the NIH in search for clues to solving this mystery. Continuing this support is absolutely essential to solving this debilitating disease.

Thank you, sir.

[The prepared statement of Martin A. Stevens follows:]

[Pages 1536 - 1537--The official Committee record contains additional material here.]

Mr. Porter. Mr. Stevens, when you talk about the progression of this disease, the progression doesn't necessarily lead to cancer of the prostate, is that correct?

Mr. Stevens. That's correct, but the kicker that we are learning now is that when they remove a prostate from somebody who's had prostate cancer, they do find an inflammation of the prostate. The cause, they don't know. They haven't looked at it. We have asked them if they would be willing to take prostates that are removed from victims with prostate cancer, look at it to find out, is it being caused by a bacteria.

So far, nothing. No answer. The fact of the matter that, as I cited, that there is evidence now that a bacteria can cause cancer of the g.i. tract. It seems logical that that could possibly be at work here in prostate cancer. I'm not a doctor.

Mr. Porter. Is it fair to say that most men at some point in their life are affected by prostatitis?

Mr. Stevens. Yes.

Mr. Porter. Is it also fair to say that doctors don't in most cases take it very seriously? I mean, they sort of say, well, yes, we'll give you an antibiotic and go home.

Mr. Stevens. That's exactly what happens. In fact, the first thing that usually brings an older man, somebody in his 50s or so to a doctor, is trouble urinating. He will find upon examination that the prostate may be swollen, that's called BPH, or benign prostate hypertrophy.

We don't know the cause of it. We think that in that case, there is evidence, or there would be evidence if they looked at it, of bacterial infection.

Mr. Porter. BPH and prostatitis are not the same thing?

Mr. Stevens. No, they're not. They're not classified at the present time as the same thing. We feel that, in fact, Dr. John

Kreeger at the University of Washington just recently published a paper of people who had prostatitis but had no symptoms, or they couldn't grow any kind of bacteria from it. So he biopsied the prostate, and they found evidence through a DNA examination of these bacteria, typical bacteria.

For instance, with me, I have a staphylococcus infection. The same bug that's on your skin, that's called staphylococcus epiderma, it's the same thing. How it got there, we don't know.

Mr. Porter. Well, I think researchers have taken diseases of the prostate more seriously recently. And that's all for the good. Obviously we want to continue to nudge them in that direction if they need any. So we'll do what we possibly can to be of help. We appreciate your testimony.

Mr. Stevens. Thank you.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

Wednesday, February 4, 1998.

WITNESS

JAN SHAPIRO, NATIONAL ALOPECIA AREATA FOUNDATION

Mr. Porter. Jan Shapiro, Volunteer Support Leader, the National Alopecia Areata Foundation.

Ms. Shapiro. Good afternoon, Chairman Porter and staff. Thank you for many years of support in seeking a cure for alopecia areata, and all skin diseases. Alopecia areata is a disease that strikes over 4 million Americans. Alopecia areata is basically hair loss. For some it's a quarter sized patch that can be easily covered. For others, it's the loss of every single hair follicle on their body.

I've had alopecia areata for 16 years, just a small patchy alopecia. Four years ago, I lost all the hair on my entire body. It's now what's called alopecia universalis. I'm the support group leader for D.C. Metro area, and I'm testifying on behalf of the National Alopecia Areata Foundation, NAAF. NAAF is dedicated to finding a cure for alopecia areata. It also provides support for those with alopecia areata through publication and support group programs.

As a support group leader for NAAF, I am many times the first person outside the medical community that a person turns to with this disease. Alopecia areata strikes members of all ethnic groups, but young children get alopecia areata more often.

Hair loss has several effects. It reduces the protection for the body that the hair provides. The loss of eyelashes means that even the simple act of opening and closing one's eyes is a difficult process at times.

Alopecia areata is not just a physical problem. It has serious psychological effects on many people. Many people with this condition think they're the only ones in the world with the disease. They often go to their doctors to discover that even their physicians have very little knowledge as to the disease process.

Unfortunately in our society, the lack of information is not the only problem. People with alopecia areata are

vulnerable to stares and comments of others. A noted news anchor lost his on-air job because he was suddenly perceived as being unappealing to the public.

This lack of being appealing or being considered normal causes many people to lose confidence in themselves, and they begin to withdraw from society. Recently two families called the Foundation within just hours of each other. A parent in each of these families has alopecia universalis, just like myself.

In the first family, they have a 13 year old daughter who was just recently diagnosed with alopecia areata. In the second family, they have a one and a half year old and a four year old who were just recently diagnosed with this condition. These parents are trying to deal with the fears of what their children are going to have to go through, as well as the frustration of knowing that right now, there is no known cure for alopecia areata.

Fortunately, people can help. In many of our support groups, people learn how to help, how they can help themselves both cosmetically and psychologically. The real solution will be when we finally find a cure for alopecia areata.

Last week, one of our National Alopecia Areata Foundation funded researchers discovered the hairless gene. NAAF has raised and provided almost \$1.5 million for research studies on genetic structure of hair, the function of the immune system in supporting non-human research studies for the cause of alopecia areata.

Part of our research program is also to continue work with the National Institute of Arthritis and Musculoskeletal and Skin Diseases, the NIAMS. One of the results of this joint program was that NIAMS funded a significant study on the structure of the disease.

The National Alopecia Areata Foundation and the 21 other lay skin disease groups in the Coalition of Patient Advocates for Skin Disease Research ask that you continue to support us. With an increase of funding of 15 percent, much more can and will be done in this area.

Thank you.

[The prepared statement of Jan Shapiro follows:]

[Pages 1541 - 1548--The official Committee record contains additional material here.]

Mr. Porter. Ms. Shapiro, thank you for coming to testify. We certainly will do our best to put this as a high priority and provide the resources that are needed.

I did read about the finding of the genetic base, let's hope it's the genetic base, of hair loss. So obviously there's wonderful things happening, if we can provide the resources we will continue to make them happen.

Ms. Shapiro. It's starting, right.

Mr. Porter. So thank you for coming to testify.

Ms. Shapiro. Thank you very much.

[Clerk's note.--Information required pursuant to clause 2(g) (4) of Rule XI of the Rules of the House of Representatives

was not received from this witness or from an entity
represented by this witness]

Wednesday, February 4, 1998.

WITNESS

DANIEL V. YAGER, LABOR POLICY ASSOCIATION

Mr. Porter. Daniel V. Yager, General Counsel for the Labor Policy Association, testifying in behalf of the Association.

Mr. Yager. Thank you, Mr. Chairman.

I serve as Vice President and General Counsel of the Labor Policy Association, representing the senior human resource executives of over 255 major corporations. I appreciate the opportunity to present our views today regarding funding for the National Labor Relations Board and the Department of Labor.

I'd like to begin by commending you, Mr. Chairman, and your subcommittee, for the active interest it has shown in the last three years on the NLRB. Clearly a by-product of that interest is the achievement of a fully confirmed board for the first time in seven years. You are to be congratulated for helping to move that process along by making it clear that the funding of the board is directly linked to its legitimacy.

Despite this progress, however, you should not ease up in any way. This is clearly an agency that regardless of who is in charge needs to be watched very closely. Just last week, the Supreme Court itself, in the Allentown Mack case, highlighted the Board's frequent result-oriented approach, saying, an agency should not be able to impede judicial review and even political oversight by disguising its policy making as fact finding.

Unfortunately, one area where this disguised policy making seems to be taking place involves the so-called single facility regulations that your subcommittee has successfully foreclosed. Two recent cases cited in our testimony indicate that the board may be reaching the same results as the regulations simply through adjudication on a case by case basis.

Another area deserving your attention involves so-called corporate campaigns, where among other things, unions apply pressure on employers through governmental agencies. As one union manual, aptly titled a troublemakers handbook, succinctly observes, every law or regulation is a potential net in which management can be snared and entangled.

Under this approach, government action is being driven not by evidence of serious violations of the law, but by organized labor strategies for increasing its market share of the work force. This comes at a time when public resources are stretched thin and these same agencies, and I'm not just talking about the NLRB at this point, are seeking more funding.

We encourage you to explore the history of corporate campaign assists by the agencies in your jurisdiction. Meanwhile, as the NLRB continues to seek increased funds we suggest you examine whether the agency could better target its existing resources.

For example, the agency's jurisdiction will continue to expand on an annual basis as long as there is no updating of

the small business jurisdiction thresholds, which are still based on 1959 dollars. In addition, the agency continues to get involved in elections involving smaller and smaller units. In one recent case, the board actually conducted an election and certified a union representing only one employee.

Finally, we commend this subcommittee for its efforts to bring the Department of Labor into the cyberspace age by requiring that union financial data be made available on the internet. Given the heightened public interest in insuring the financial accountability of unions to their membership, this should be a no-brainer.

Unfortunately, it is our understanding that the Department has made little or no progress in complying with your directive, even though other comparable information is readily available through the internet from other agencies. We provided an example in our testimony.

This year we encourage you to go another step further by requiring DOL to place the advisory opinion letters regarding technical areas of the wage and hour laws on the internet as well. Currently, these are very difficult to find, and therefore employers can only guess whether their work place practices are legal in the Department's view.

Thank you for the opportunity to appear before you today. We look forward to working with you, and I'll be happy to take any questions, Mr. Chairman.

[The prepared statement of Daniel Yager follows:]

[Pages 1551 - 1560--The official Committee record contains additional material here.]

Mr. Porter. Mr. Yager, are you telling us that the agency has, there is a recognizable pattern of deciding cases that put them in the same place they would have been had they adopted a rule on single site bargaining?

Mr. Yager. That is certainly the evidence, Mr. Chairman. In the last year, I've seen two cases decided by the agency. Now, typically, these issues are dealt with at the regional level, so they're harder to track at the Washington level.

In both cases, and as you know, this is a very fact-intensive area of the law, in both cases, the regional director had looked at the facts and decided that a multi-facility unit was appropriate in those situations, not just a single unit. It was a trucking facility--I'm sorry, it was a bus facility.

Typically the board will defer to the agency's decision. I mean, they're out in the field, they know all the facts and circumstances. In both cases, they came up to the board and the board reversed the regional director. In both cases, there was a dissent by Member Higgins on the board.

Mr. Porter. Is this case that you mentioned in the Supreme Court, does that deal with this subject matter?

Mr. Yager. Similarly--no, it's a different subject. It deals with withdrawal of recognition from a union. They are calling attention to this pattern where the board will make a fact based determination, they'll say, we're not doing anything to change the rules. In effect, they change those rules by sort

of looking at the right set of facts to reach the same result they would have reached if they would have changed the rules.

Mr. Porter. As you know, many members of this subcommittee have been very concerned with the way this NLRB has approached the law that it is to administer. There have been a number of attempts to try to curb some of the things that members see as excesses of the board. And there's been, I think it's fair to say, a great deal of tension between the subcommittee and the NLRB over the last few years.

I think you'll see a great deal of attention paid to this subject again this year. Last year, year before, year before that, each of the last three years, we have attempted to send messages by restraining budget. This is not the best way, in my judgment, to do that, because this is a body that is supposed to be resolving disputes between management and labor under the rule of law. Any time you restrain budgets, you can get the reaction of simply creating backlogs that probably don't serve anyone's interest.

On the other hand, there are things that members have been very concerned about reaching, and we've had a number of meetings between Chairman Gould and members of the subcommittee in an attempt to resolve these matters.

If I were to find that there is a pattern here, as you describe it, of getting around what the subcommittee had exactly told the NLRB not to do, and that is adopt a, basically adopt a rule on single site bargaining, that would be very serious indeed.

So let me thank you for your testimony, for bringing these matters to our attention. I will be interested to share your testimony with members of the subcommittee and draw it to their attention. We appreciate knowing what you've provided to us. Thank you so much.

Mr. Yager. Thank you, Mr. Chairman.

Wednesday, February 4, 1998.

WITNESS

JOAN I. SAMUELSON, PARKINSON'S ACTION NETWORK

Mr. Porter. Last but not least, Joan I. Samuelson, J.D., President, Parkinson's Action Network, testifying in behalf of the Network.

Do I call you Dr. Samuelson, since you're a juris doctor?

Ms. Samuelson. Absolutely not.

Mr. Porter. Well, wait a minute, I am, I might want to be called that.

Ms. Samuelson. Well, perhaps. I sometimes receive letters with that, and I kind of enjoy it. I find that working with the scientific community, I felt extremely lonely at times when everyone on a list of people would have initials after their names. I don't particularly like using the initials, but sometimes I feel a member of the club.

I must begin by saying, I feel a bit of compassion fatigue just sitting here this morning. So I must just tell you how I appreciate the scope of your committee, the immense number of human problems that you have to address.

In particular, your incredible leadership in the area of biomedical research. You have challenged your own body, you have challenged the Senate. Now even the Administration is rising to the call. I appreciate that personally from the bottom of my heart and on behalf of the Parkinson's community. It's been an enormous support for all of us.

Having said that, what I have to do is beat our drum a little more. I thought what I would do is just talk about a few highlights, then try to address the things that I know are of concern to you. Jim Cordy did a marvelous job of describing the necessary desperation with which we conduct our lives, every day waking up knowing that we're that much closer to the fate that many people we love are currently suffering.

I know, I'm 11 years post-diagnosis. On Mo Udall's timetable, I've got a couple more years before I'm struggling terribly, and perhaps will take a terrible fall, as he did, which will really end my ability to live a productive life.

On the timetable of a close friend, Millie Condrachey, Mort Condrachey's wife, I am overdue of the time when I would be relegated to walker or wheelchair and really unable to do this work. She used to accompany me in meetings on the Hill. Now it's treacherous for her to get anywhere, because she falls so frequently. She falls almost daily. Her voice is now so soft she really can't communicate unless someone is extremely close.

I live with the same urgency that Jim does. He did a lovely job of describing it, and I know you've heard it before.

Why do we need the Morris K. Udall bill funded to its fullest, to \$100 million in Parkinson's specific research? And why Parkinson's specific? I know that's a concern of yours. That's what I'd like to spend my time talking about.

The first is simply the enormous research potential. One thing I know the scientists in the Chicago area have talked about doing is bringing you to their lab. I'd like to help them try to arrange that. There's just tremendous work going on at Northwestern, Chicago Med School, the University of Chicago. In fact, one of them called me to tell me they've been on the phone talking about a collaboration to apply for one of the Udall centers that are proposed in the Udall bill, and a preliminary approach to that is being considered right now by the NINDS.

I think in anticipation of the Udall bill's passage, they sent out an RFP in the fall and the proposals are due in April, so we don't really know the number that they will fund. The RFP is for up to three, and I'm sure they're going to get a virtual flood of proposals.

This incredible research based in basic science, fascinating collaborations among basic science and clinical research, going on all over the country. And it's enormous backlog, because Parkinson's research has not been funded historically.

I attached to my testimony two charts. One is a horizontal chart which shows Parkinson's funding over the last decade plus. It's just a very sad picture. It's essentially stagnant, the entire time. When Parkinson's advocacy really was in its infancy, in 1991-1992, the NINDS advisory council issued a report in which they said that by the end of the decade, there would be, with adequate funding, available therapies that would

prevent or reverse Parkinson's. Which is of course exactly what we need, as the medication begins to cease its effectiveness.

They're not there yet. They're very close. But they're not there yet. And it's because that money has been slow in coming. It's directly attributable to that, and it's just a terrible, terrible shame for the many people who may be beyond hope, as well as the rest of us who are so desperately hoping that the treatments will be delivered by the time we desperately need them.

For that reason, I feel that the intent of the Udall bill must be funded to its fullest, with Parkinson's specific research. I know that's a concern of yours, both in terms of the notion of earmarking and the fact of focusing in on a given disease. The pent-up supply of incredible research opportunities is enormous, and is pent-up, and all deserves to be funded. There's far more that could be funded than money available, or that even in the President's proposed budget would be.

It really has to be tackled aggressively, so that the cure will be delivered as soon as it can be. It's later than it should have been, but as soon as it possibly can be.

So how do you do that? We feel we must focus in on Parkinson's specific research because we have been neglected in the past. That doesn't mean it should be coming from other diseases. What we have to do are the things you recommend, we have to work with the budget committees. We have to work for the doubling of the NIH. We will do everything we can to work with you to do that.

I'm offering all the help that the Parkinson's community can give to lead the battle. Thank you, Mr. Chairman.

[The prepared statement of Joan Samuelson follows:]

[Pages 1564 - 1574--The official Committee record contains additional material here.]

Mr. Porter. Ms. Samuelson, I appreciate your testimony. I'm glad you brought up Morton Condrachey's wife, because I think it's fair to say that there's no one that's been a stronger advocate, more persistent, aggressive leader on addressing the whole issue of Parkinson's research than Morton Condrachey. Largely because of, and I wasn't originally a part of this, but my understanding is that largely as a result of his efforts, this matter got pushed as far as it has been.

I want to be very clear about one thing, though. We do not fund bills, we fund institutes. As you know, you've alluded to this in your testimony, we are very careful to leave the final determination of where the opportunities in science lie and where the best chance for the funding to make a difference in peoples' lives lie with science.

That does not mean that we simply rubber stamp what NIH suggests. As you know, we're very active and very aggressive in pushing things that we think are important on NIH, without directing. In other words, we don't go the final step and say, you have to do this. We believe if we did that, we would be substituting our political judgment and we are not experts for

scientific judgment that always has to prevail in these areas.

I think it's fair to say, and I think NIH would say that we go very close to that, and do suggest very strongly to NIH what our thoughts and priorities are in respect to funding. I think it's also fair to say that working with NIH, they have traditionally been very sensitive to the concerns expressed by Congress in the bill and the report accompanying the bill. NIH has been very responsive in terms of what our own priorities would be in a broader sense of, rather than a disease-specific sense.

I think all of us consider this a very, very high priority, and we're going to push very hard for it. As I said, we have not only Morton, but we have several members of Congress who are very strongly pushing the NIH and the subcommittee on the subject. I think the message is being heard, and I think you can look forward to Parkinson's being placed at a higher priority in the immediate future and the long term future as well.

There seems to be, again, we're not experts, but there seems to be so much progress being made, and we're so close, it would be a shame if we could not get the additional resources placed there that would bring about real serious progress that would make a difference in your life and Mr. Cordy's life and others who suffer from this disease.

We'll do our darndest.

Ms. Samuelson. Thank you, Mr. Chairman.

I'd love to get you together with those scientists in the Chicago area, because they could really describe the difficulties they've had in getting their Parkinson's research funded. It's partly simply there hasn't been enough money in the neurological institutes. Of course, the brain hasn't receive the attention it's needed.

It has seemed to be more than that. The reason, I think, there's been the Congressional response. And I know about your reluctance.

Mr. Porter. I'd be happy to meet with them, and if we see a problem beyond the simple lack of money, we'd like to address that. Absolutely.

Ms. Samuelson. Great.

Mr. Porter. You arrange it, and we'll do it.

Ms. Samuelson. Good deal. Thanks very much, Mr. Chairman.

Mr. Porter. The subcommittee stands in recess until 2:00 p.m.

Afternoon Session

Mr. Porter. The subcommittee will come to order.

This is the eighth of nine sessions hearing public witnesses before this subcommittee. We appreciate very much all of your attending and providing us with your views and knowledge.

Because we have so many witnesses that want to testify, we have to pay very close attention to the time that allot to each witness. I will tell you now that the subcommittee is now armed with a timing device that you will hear go off if you go beyond the five minute time limit. We simply ask that you, in the interest of everyone else getting a chance to testify, observe

as closely as possible the allotted time.

I suspect that in the course of the testimony, you will hear a couple of sermonettes from me that I've given to each of the panels. Please bear with me with those.

Wednesday, February 4, 1998.

WITNESS

CHARLES BALLARD, NATIONAL INSTITUTE OF RESPONSIBLE FATHERHOOD AND FAMILY REVITALIZATION

Mr. Porter. We'll begin with Charles Ballard, the Founder and CEO, National Institute of Responsible Fatherhood and Family Revitalization, testifying in behalf of the Institute.

The Chair recognizes Mr. Stokes.

Mr. Stokes. Thank you very much, Mr. Chairman.

It's indeed a real pleasure for me to have the opportunity to welcome before this subcommittee a gentleman who comes from my Congressional district, and a gentleman for whom I have, over a number of years, had the highest esteem. He has been founder of an organization that has taught fathers to be responsible to their families and to their children in a way that I've seen no one else approach that type of responsibility.

His institute has now been the beneficiary of funding through this subcommittee on a competitive basis, through the Department of Health and Human Services. The program now has become so good it has now spread out, it has gone national and exists now in several cities.

I just want to say that Mr. Ballard is an exemplary individual, and someone we're very, very proud of. It's an honor to have you before us.

Thank you, Mr. Chairman.

Mr. Porter. Thank you, Mr. Stokes.

Please proceed, Mr. Ballard.

Mr. Ballard. Good afternoon, Mr. Chairman, Mr. Stokes and members of the committee.

It's a great pleasure to appear before you this afternoon and share with you the burden of my heart which I think affects not only us here but affects America. It's an issue that I call fatherlessness. Fatherlessness is not just simply a man not at home, but it's even a man at home but he's not being responsible for his family. He's not taking care of them, he's not being a good nurturer, a good provider, and other kinds of things.

This approach that we take started in Cleveland about 20 years ago, is helping men of all races, creeds and colors, but especially those who are in disrepair, to be good men, and to be responsible men toward their children.

I need to share with you why it's such a burden to me, because I grew up in Alabama back in the 1930s, 1940s, and 1950s. I experienced this same problem. My dad, because of whatever reason, became mentally ill and was taken out of the home, where he later died in an institution. I grew up without a father, and did things that many guys do, got in gangs and did drugs and all. Then I got a girl pregnant and ran away,

joined the armed forces, got more involved in drugs, ended up in prison.

While I was in prison, I met a man who I would have considered, someone like Mr. Stokes, who was compassionate, understanding, and who reached out to people and who cared. It was very unusual for someone behind bars to be that way, so he really attracted my attention.

He worked with me very patiently and gave me a lot of time and introduced me to God and Jesus Christ. I overcame drugs and alcohol and went back to Alabama in 1959 to get my son. I had a prison record, I was undesirably discharged, I hadn't finished high school. But I took on my son, I adopted him and began to raise him. Of course, with those kind of records, you couldn't find jobs.

I didn't care about that. I was concerned about caring for my child and making sure he did not grow up like that. So I took any kind of jobs, dishwashing jobs, floor scrubbing jobs, and I went on and got my GED, a B.A. degree, and I have a masters degree now.

When I got my masters in Cleveland, I went to a hospital to work, my major purpose was to help me to understand that it was their job, not government, not welfare, to care for their children. I would say, if not for people like Mr. Stokes, who not only supported it locally but nationally, I would not be here in this place. Because of his support and his direction, foundations and governments from around the country have funded our program.

I appear back here today to not only share with you the problems, but to show you what we've done and make some recommendations. I was amazed to discover that here in America we have more women going to prison than ever before. From 1930 to 1950, we built four women's prisons. From 1980 to 1990, we built 33 women's prisons.

We've built more prisons in a span of 10 years than we did in 30 years. One of the reasons I believe is because we have many men going to prison and women are following their boyfriends and husbands behind bars, and leave the children vulnerable for substitute care.

Just recently, Congress passed a bill and the President signed it to have adopted 100,000 children. That's great, out of the 60,000 kids in substitute care, mostly African-American kids, but we need to go farther. We need to bring fathers back to their children as loving, compassionate men. This program that we started that has now gone nationwide is designed to do just that. Every city we've gone into the last two years, we have planned to raise 25 fathers per site. The need is so great, the first year there were 65 fathers per site in 6 cities.

Now, in coming today, I wanted to look at doing something not just to get money, but to do something special. As I sat here, people from other States were shaking hands with Mr. Stokes. I've seen him do other things with other States, so his name is kind of like around this country.

I was told he's going to retire very soon. To me, that's a major tragedy for us as a country, unless somebody replaces him that's as good as he is.

I would like to suggest more funding for this agency to go

into other sites, other cities. What I want to do is name this program the Louis Stokes Responsible Fatherhood Initiative, so around the country, as this program spreads out and becomes more pervasive, the person who has given us the most support out of Cleveland will now have his name in this way around the country.

Here is what I'm suggesting. When I came before, \$500,000 was given to us in Cleveland for that one program. Of course, since that time, we have advanced into California, we're in Nashville, Tennessee, Milwaukee, Wisconsin, Yonkers, New York, here in the District and of course, Cleveland, Ohio. Letters are coming from all around the country as we are placed on national TV and asking for this program to come to their city. We've chosen 10 new cities to go into.

What we're suggesting is that this committee appropriates \$500,000 per site, for a total of \$8 million, and that the committee also appropriate \$500,000 to create a responsible fatherhood clearinghouse, so that agencies around the country can better understand the plight that these men have, seeking to be involved with their children. And that we also appropriate \$500,000 for research and evaluation to see the power of this program, and what we actually do with these men, so we can replicate it even more into other areas.

Let me show you why this is so important. Within the first six months of this program, men who have not had jobs, will find jobs and begin to pay child support. There is a great concern about men paying child support in this country. Some men cannot, because they don't have jobs. Through our program they find jobs.

Domestic violence, which is a serious issue among women that we interviewed, becomes almost zero in six months. Gang membership, gang banging, goes to zero. The program not only affects the man with his child, but with his girlfriend, with the community, and with also getting gainful employment.

We also discovered that at least 20 percent of these men get married. In the welfare reform bill that was authored by Mr. Shaw, marriage was one thing they suggested was happening. Our guys are getting married, they're coming back home, and they're being responsible for their children.

Thank you very much for this opportunity to share this with you.

[The prepared statement from Charles Ballard follows:]

[Pages 1580 - 1596--The official Committee record contains additional material here.]

Mr. Porter. Mr. Ballard, tell me again what line item this is funded under? Your current funding is under what agency?

Mr. Ballard. It came under the Health and Human Services.

Mr. Porter. Innovative programs. All right. Well, we certainly share your feelings about Congressman Stokes and the wonderful contributions he has made. I think it's a real honor, I'm sure he does also, that the program would be named for him.

Obviously we want to do the best we can to fund programs that work for people. We will do the best to look into it

further and provide the kinds of resources that are needed.

Mr. Ballard. Thank you very much.

Mr. Porter. Thank you for coming here to testify.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness]

Wednesday, February 4, 1998.

WITNESS

WARREN GREENBERG, MENDED HEARTS, INC.

Mr. Porter. Warren Greenberg, Ph.D., Chairman, Committee on Lobbying and Legislation, representing the Mended Hearts, Inc.

Dr. Greenberg.

Dr. Greenberg. Thank you very much, Mr. Chairman. My name is Warren Greenberg. I am a professor of health economics and of health care sciences at the George Washington University. I am married and have a 23 year old daughter.

I am here to testify for an increased appropriation for the National Heart Lung and Blood Institute. I am a victim of heart disease, and a beneficiary of the efforts of medical researchers to overcome this disease.

I might also add that I am a member of Mended Hearts, a support group of 24,000 members throughout the United States, including the Chicago area, the Cleveland area, and I have been appointed lobbying and legislative chairperson of the Mended Hearts group, a volunteer position.

I am 54 years old. I was born with aortic stenosis, a narrowing of the heart valve. Throughout my entire life, I have lived with heart disease, often incredibly severe. When I was in my early teens, my physicians did not allow me to play high school intramural sports, although I was a fine athlete. At the age of 18, I was told not to play ball under any circumstances.

In my early 20s, I was told not to climb more than two flights of steps. By my early 30s, I began to climb steps more and more slowly, often pausing to rest. I never carried an attache case home from work. It was too heavy.

I would often balance a large book on my hips, rather than carrying it outright, in order to blunt the weight. I would walk two or three blocks on a level street to avoid going up three or four steps at the ends of particular blocks. I could barely lift my newborn child. I could not help my wife take in the grocery bags.

In May 1982, at the age of 39, I had open heart surgery at the Cleveland Clinic to replace my diseased valve with the valve of a pig. After my six week recuperative period, I was amazed to find that not only was I able to walk, but was able to play tennis, to jog and to exercise. I was able to live a normal life.

By August, 1988, however, my new valve had failed. In August, I again had cardiac surgery at the Cleveland Clinic to replace the failed pig valve with an artificial plastic valve. I am again able to live a relatively normal, very productive life. And I am deeply thankful for it.

I take a blood thinning medicine, coumadin, which helps prevent clots on my new valve. At the same time, because of the medicine, I must be cognizant and careful of excessive bleeding. In 1983, I contracted endocarditis, an infection of the heart valve, which kept me in the hospital for six weeks. Whenever I have dental work now, I get intravenous penicillin to protect me against such infections.

I realize that my valve, as a mechanical device, might fail at any time.

For nearly 16 years, thanks to the fruits of medical research, I have been able to travel abroad at least once a year, to jog in the park, to be a productive author of many scholarly articles and a number of books on the health care economy. I have been quoted often on my views on the U.S. health care system, and have made many television appearances.

If it were not for the advances in research leading to improved techniques in open heart surgery, I would not have seen my 40th birthday. I would not be able to look forward to a life of many rewards and enjoyments.

As an economist, I always observe the link between monetary resources and the development of innovation and technology. Health care research and cardiovascular research is no exception.

I also understand as an economist that there are always competing uses for the monies that you appropriate. However, cardiovascular diseases last year killed more than 960,000 Americans, of whom more than 154,000 were under the age of 65. Despite advances in medical research, these diseases remain the number one killer in the United States and a leading cause of disability.

From my personal perspective, and for those at Mended Hearts across the country and others in the United States who have heart disease, or who will get it in their lifetime, I ask for a doubling of the National Heart, Lung and Blood Institute budget within five years. To reach this funding goal, I advocate a fiscal year 1999 appropriation of \$1.825 billion for the National Heart, Lung and Blood Institute, to help reduce further the incidence and degree of heart disease in this country.

[The prepared statement of Warren Greenberg, Ph.D. follows:]

[Pages 1599 - 1605--The official Committee record contains additional material here.]

Mr. Porter. Perfect timing.

Dr. Greenberg. Thank you, Chairman.

Mr. Porter. Dr. Greenberg, thank you for your good statement. You're going to be the recipient of my sermonette number one.

This subcommittee has placed, as you know, biomedical research at a very high priority. We think that that is proper, not only from the standpoint of improving and saving lives, but from the standpoint of saving health care costs as well. Research saves costs.

We share the goal that you have just mentioned, at least I do personally. I think members of the subcommittee do as well. We are going to have a tough time reaching it without getting the kinds of allocations from the budget process that we need to reach those goals. This applies not just to biomedical research, it applies to all the matters under our jurisdiction, many important programs that serve people and improve their lives, and serve those most at risk in our society.

Our plea to those who have come to testify and ask for greater funding is that they not only pay attention to the appropriations process, which obviously they are, but they also pay attention to the budget process, which is where the funds come from that allow us to do our work. I think everybody realizes this, but John Kasich and his subcommittee in the House and Pete Domenici and his committee in the Senate are very important to all this process, and the place where the allocations derive from which we are able to do our work.

We hope that you will pay as much attention to them as you do to us. That's sermonette number one. Two comes later, but that's number one.

Thank you very much, Dr. Greenberg, for your testimony. We will obviously do our best.

Dr. Greenberg. Thank you, Chairman, and members of the committee.

Mr. Porter. Thank you so much.

Wednesday, February 4, 1998.

WITNESS

MORGAN REYNOLDS, NATIONAL CENTER FOR POLICY ANALYSIS

Mr. Porter. Dr. Morgan Reynolds, Senior Scholar, National Center for Policy Analysis, testifying for the Center.

Dr. Reynolds.

Dr. Reynolds. Thank you, Mr. Chairman and committee members.

I appreciate this opportunity to testify today about downsizing labor bureaus and agencies of the United States Government. My name is Morgan Reynolds, and I am a senior scholar with the National Center for Policy Analysis. I'm also a professor of economics at Texas A&M University in College Station, Texas.

I've done four books on labor issues, including a recent textbook, economics of labor. I'm a member of the board of the Journal of Labor Research.

Last year, the President's Council of Economic Advisors wrote in its annual report, ``Over the long run, sound economic policies that lead to low levels of unemployment and high rates of economic growth are likely to produce gains for most workers.'' True enough, but the Council was unwilling to back the market wholeheartedly, declaring instead, ``Government has a role in lessening the burden that economic growth causes for some workers.''

The Constitution is strangely silent on this Federal authority to protect employees from the gales of creative destruction that characterize the market process. We've got a

colossal structure of Federal labor controls that can't withstand careful, rational examination. Like the welfare state itself, it appears to emotion, rather than reason.

Why the invisible hand of market competition, aided by ordinary property, tort, contract and criminal law, cannot be trusted to work out the ordinary difficulties of daily life has never been satisfactorily answered. There is no evidence that labor markets have failed with consequences so horrendous as to call for the daily microtuning by the mighty and mighty expensive visible hand of the United States Government. In fact, these bureaus depress business growth and thereby impoverish Americans.

Companies, not government, must control hiring, firing and promoting employees. As English economist David Ricardo wrote in 1817, ``Wages should be the result of a free compact, and the contracting party should look to the law to protect them from force being employed on either side. Competition would not, I think, fail to do all the rest.''

In the name of protection for workers, regulation begets regulation and spending grows. One of the more absurd consequences has been an effort to impose our labor protections on other nations, long before they can afford such folly. On-budget spending indicates only the dead weight administrative cost of labor regulation, not the full cost to working people.

Federal agencies by and large serve political rather than economic ends, and we lack the ultimate discipline of bankruptcy for programs, which we have in the private sector, obviously. Every dollar government spends is received by someone, and I know that some of them are here today. The recipients have more to gain from preserving a losing venture than from dissolving it.

The era of big government, paternal business, and paternal unions, has a limited future. We're seeing it being played out in Europe at an advanced stage. Existing employment policies are 65 years old and based on an outmoded welfare state philosophy. Too many Americans live paycheck to paycheck, backed precariously by a frayed safety net. It's time to implement a new philosophy. We should promote a society of free, responsible and self-reliant individuals instead of fearful and dependent ones.

How can we take pride in expanding the Federal Government and reliance on it while our wealth grows? We should aim at new policies that allow maximum opportunity for individuals, families and generations to pay their own way. I call that the American way. An empowerment agenda meets the needs of a more flexible work force.

Growth depends on low rates and marginal taxation, especially on capital income, to increase capital formation and add new technologies through R&D. Improved labor quality must come from a competitive, decentralized and innovative educational and training system. A stable political environment with stable price level and low interest rates must come from government, as must reforms in our institutional arrangements to increase growth.

Empowerment for individuals and families awaits expansion and enactment of pro-market reforms, such as medical savings accounts, privatization of social security and broadening of

401(k) type accounts. These should be adopted not only to rationalize the markets in health care and prefund retirement, but to boost total savings and investment and thus jobs, real wages and financial security.

Given this market approach, we obviously have a target rich environment for downsizing labor agencies and deregulating our labor markets. The Cato Institute has proposed, for example, terminating special interest departments like Commerce and Labor.

Thank you.

[The prepared statement of Morgan Reynolds follows:]

[Pages 1609 - 1614--The official Committee record contains additional material here.]

Mr. Porter. You didn't have to stop quite that abruptly.
[Laughter.]

Dr. Reynolds, first I'd like to ask what bureaus and agencies were you specifically referring to in the first part of your remarks? Were you talking about OSHA and MSHA and NIOSH?

Dr. Reynolds. Well, I'll take partial or complete repeal of the appropriations for agencies. My little laundry list here had eliminate Federal training programs and the Federal role in unemployment insurance, and leave it to the States to experiment, since they will do a better job. Repeal Federal regulations governing hours and wages, leaving Americans free to bargain for their own terms of employment in a competitive market place.

Take a more neutral position between business and labor in their disputes, ending restrictions on employee-employer cooperation and negotiation, or even appealing the National Labor Relations Act, which is the overarching legislation passed in 1935. Yes, eliminate Federal oversight of the work place. Relying instead on a combination of tort law, workers comp programs and market wage differentials to promote an efficient amount of safety.

Mr. Porter. Let me say, the philosophy I believe you are laying before us is maybe not in its pure form, or even close to it, but largely being followed. That is, we are attempting, as you know, at least for the last three years, to examine every way that the Federal Government spends money, go through every single program, to wherever possible move programs where it makes sense to a different level of government, to the States, to the local communities, to the private sector, to eliminate those that don't work or are unnecessary, to examine all of that in light of are we getting what we're paying for.

That may be a more pragmatic view than what you would like us to do, but I think very definitely there is, and I don't like the word devolution, but I think there's very definitely an attempt here in the Congress to devolve a good deal of what the Federal Government has come to have jurisdiction over to State and local governments. We've gone through, as you know, a period of history beginning perhaps with the Great Depression through World War II through the Cold War that concentrated an

awful lot of power in Washington that was not originally here, and was in fact exercised by the States and local communities.

I think we're moving in a lot of the directions that you have suggested. I personally have the major legislation to privatize social security. It's my bill. I introduced the first bill to do that in 1989, when nobody even wanted to talk about social security, let alone privatizing any part of it.

I think we are now in a position where in fact we can form the kind of social security system that we would have formed in the middle of the Great Depression if we could have, and that is, a vested, funded system owned by the workers and not by the government. I think we're on the verge of being able to do that, if people can have a little imagination.

We've got a foot in the door on individual medical accounts, that is a small pilot program, it's true, under Medicare. But it's there. I think some progress is being made along these lines.

I don't think I agree personally with the views that you have, and I'm not sure whether they're libertarian or laissez faire or a combination of the two. But I'm not sure I agree that the government can back out of certain worker protections. I think that there has been, unfortunately, a history that we are largely overcoming, and we can do things entirely differently. But until we turn that corner, I think we're going to need to provide some basic protection to workers.

We have an OSHA today for example, that has changed its philosophy completely. It hasn't gotten down to the lowest levels of enforcement, but if you talk to the director of the program, in Washington, the idea is not to have raids on employers and fine them for every little thing that they find. The idea is to get their cooperation and work with them to provide a safe and healthy work place for American workers, and only to use the enforcement powers where you have a history of not caring about those conditions in the work place that lead to greater safety and health.

I think we're doing things smarter than we did before. Maybe our approach is more based on pragmatism than on philosophy, as you might wish it, but I think it's moved largely and fairly substantially in a short time in the kinds of directions where we're doing things better and doing less in Washington and leaving more to the private sector and more to the other levels of government.

Dr. Reynolds. If I might respond.

Mr. Porter. Yes, sir.

Dr. Reynolds. I certainly agree with that, the trend is clear. I also wanted to note that in my prepared statement, I say that the harm from labor regulation has been contained because the Congressional majority always fears the business destruction caused by such regulation, and so limits its attempts to put this flawed theory into practice. I think that's what's gone on, for example, with OSHA reform.

Mr. Porter. I also believe, and the real progress isn't here in Washington, the real progress is out there in the private sector, where we have an employer community that is much more progressive and caring about the fate of their workers than it used to be, or at least the evidence points to a different philosophy in the past than I think is exhibited by

most business people today.

The problems that once existed are very much less, because I think labor and management increasingly are seeing their destinies as being tied inextricably and their success dependent upon one another, which is exactly where it really has always been, very frankly. You can't have one without the other. Both have to prosper and go forward.

Well, we could discuss this at some length. Mr. Miller, I expected you might.

Mr. Miller. One of the frustrations you brought up this morning about appropriations versus authorization, and we can only do certain things at the appropriations level. We have made some progress. You mentioned OSHA. We have shifted resources from enforcement, the police action, versus the classification compliance, which is a little different from sending in the police and such and get people to work to resolve an issue. There are problems there.

You mentioned NLRB. First year we had control to slash the budget 30 percent in the House, but it didn't work out in the Senate. So it's a frozen budget, and the cost of living changes and affects our changes, it really means a cut. There's only so much we can do, but we need to keep addressing it.

A lot of it goes back to laws in the 1930s or 1950s, the threshold, for example, one issue we've talked about with NLRB, the threshold is like \$50,000 in payroll costs before they can get involved. Well, that's a very small amount. If you adjusted that to inflation, you'd be up at a half a million dollars. That's where you should be.

We're trying. We appreciate your bringing your thoughts to us on the issues. Thank you.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

Wednesday, February 4, 1998.

WITNESS

JOE CIPFL, ILLINOIS COMMUNITY COLLEGE BOARD

Mr. Porter. Dr. Joe Cipfl, President and CEO, Illinois Community College Board, Springfield, Illinois, testifying in behalf of the board.

Joe, nice to see you.

Dr. Cipfl. Nice to see you, Congressman Porter, and I certainly want to express appreciation for having the opportunity to appear before you today. I assure you, I come before you today proudly from the State of Illinois, the home State of Chairman Porter. Certainly, Congressman, we want to thank you for your great leadership and the commitment that you've given to community colleges in our State.

What I would like to do this afternoon is to assure you that community colleges are prepared for the opportunity to play an expanded role as policies and budgets are developed, particularly in welfare to work programs and work force training programs. Two issues that are fundamentally important

at this point in time in the history of the State of Illinois, and certainly the history of our Nation.

I think it's important to acknowledge this afternoon that community colleges at this point in time are the largest sector of higher education in our Nation. Nationwide, in fiscal year 1997, community colleges enrolled 5.3 million credit students and approximately 5 million non-credit students.

Illinois has the third largest community college system in the Nation. This past year, we served in excess of one million students, literally one out of every ten Illinoisans are currently enrolled in a community college.

The average age of those Illinoisans is 31 years of age, that are enrolled in community colleges, a very adult population. A group of individuals who thought they had skills to last them a lifetime, and in this technological revolution in which we're all trying to survive, found out that they had to literally return to the classroom.

I think it's important to note also in Illinois that 63 percent of the students enrolled in public higher education are attending community colleges. In Illinois and nationwide, we are the primary provider.

Welfare reform ranks high on the national agenda. And it is true in Illinois. Helping welfare clients fulfill their potential and acquire the skills for gainful employment ranks among the top priorities of the Nation's community colleges.

A work force emphasis accompanies recent legislative welfare changes. Illinois community colleges are responding to this need with a powerful program called Expanding Opportunities. In partnership with the State's department of human services, this program places an emphasis on short term occupational certificates and skill building courses that are designed to help people quickly develop skills for upwardly mobile employment.

Expanding Opportunities has moved literally thousands of people from the welfare rolls to the work place. This model program can and should be replicated, and it can work in States throughout the Union. We need to expand these programs and those like it, taking folks from welfare and putting them in the work place.

In one accessible location, community colleges provide the array of programs and services necessary to move people, at an accelerated pace, from welfare to work. Today's world also demands an increasingly skilled work force, and an educated citizenry.

I think it's important to note that by the year 2000, 89 percent of the jobs in the United States will require post-secondary levels of literacy and post-secondary levels of math skills. Only half of the new workers coming into the work force are likely to have those skills.

This skills gap will create increasing disparity in wages, unless corrective action is in fact taken. I would suggest to you that community colleges are uniquely positioned to help workers compete in a marketplace that demands heightened levels of competency. The colleges provide credit generating work force training course work in hundreds of different occupations. Community colleges also offer customized, flexible, non-credit training for business, for industry and

for government.

For example, in fiscal year 1997, Illinois community college business and industry centers provided technical assistance to 2,300 businesses and 76,000 employees. Through economic development activities, these centers helped create or retain over 165,000 Illinois jobs in the last five years alone.

This afternoon, I want to applaud your identification of education, and particularly higher education, as a top priority in the budget process. Our citizens place a great trust in community colleges to provide a skilled, American work force, one that can compete successfully in a competitive, global market place. Funding for community colleges helps sustain the communities that serve communities from which we all draw our educational and our political nourishment.

One final point, if you will allow me. Nationwide, tuition and fees for the average full time community college student are only \$1,500 a year. This low cost is certainly a remarkable educational value. But there is still a very real need for financial aid among our students.

Many low and middle income families are taking advantage of the Hope Scholarship Tax Credit and will benefit from continuation of this program. Thank you.

The increase in Pell Grants achieved last session is laudable, but more needs to be done. Nationwide, a need exists to provide a Pell Grant maximum for fiscal year 1999 that is greater than the \$3,100 requested by the Administration. Providing increased income protection allowance proposed by the Administration will also enhance educational access. The Title III(a) strengthening institution programs is a key initiative for community colleges.

I urge you to fund it at the \$80 million level in fiscal year 1999, Congressman Porter, that you support it. Your support of Pell Grants, along with other financial aid, such as Perkins loans, helps maintain the rich diversity of community college student bodies. This aid makes a quality higher education truly accessible to all who desire it.

In summary, I would suggest to you that America's community colleges have truly emerged as the vanguard institutions for preparing workers and their companies for the challenges ahead. Our community college systems exemplify low cost, high quality post-secondary educational opportunity empowerment.

Thank you, sir.

[The prepared statement of Joseph Cipfl, Ph.D., follows:]

[Pages 1620 - 1622--The official Committee record contains additional material here.]

Mr. Porter. Dr. Cipfl, can I ask you a question about costs? This may not be a fair question for you, but you may know the answer to it.

There's great concern that as we make increases--excuse me a second.

There's great concern that as we increase the assistance through Pell Grants and loan programs for students for higher education that the costs of that education rise to meet and

sometimes exceed the increases. We are left not having made any progress at all. Can you comment on that generally?

Dr. Cipfl. I would be happy to comment on that, sir. Certainly the suggestion that available dollars cause us in higher education to elevate our costs I think is an issue that needs to be addressed.

In Illinois, we've identified two particular initiatives. One is PQP initiative, priorities, quality and productivity. We're attempting to very carefully examine our unit costs. The dollars that it truly takes to provide, literally, a college credit hour. Rather than simply elevating those costs, we're attempting to document the implication of those costs.

I believe that is an issue that can be raised, but I think the higher education community is prepared to in fact not only defend but explain and validate the costs that we're incurring, literally, in this technological revolution. I would suggest to you today that the strength that this Nation's economy is enjoying can be at least in part, I think, attributed to what's happening in the higher education arena today. That in fact the technology that's being developed, the technology that's being impacted, that's impacting the strength of the economy, that education has played a role in that. I guess we would ask for a reinvestment.

But I think we're prepared to explain our costs.

Mr. Porter. Joe, that wasn't a hostile question. It was an access question.

Dr. Cipfl. Oh, I understand.

Mr. Porter. What we're concerned about is that if the costs rise as fast as or faster than the resources we add, we don't get the increased access that we're trying to achieve. It's not that they're not justified, or that they're not working overall in respect to improving the quality of the education that's being offered. But how do we get the access if they're absorbed. That's really what I was concerned with.

Dr. Cipfl. Well, since I'm here speaking in behalf of community colleges----

Mr. Porter. As I said, it was probably an unfair question.

Dr. Cipfl. Oh, no, I love it. You know, the cost of community colleges I believe address the access issue. When you talk about access, I assume you're talking about student access. I think it's important for the community colleges in this Nation to continue to elevate their ability to provide. Really, when you're talking about that baccalaureate degree, I would suggest to you that costs can be considerably curbed if the freshman and sophomore year of that baccalaureate degree become the primary responsibility of this Nation's community colleges. You will save lots of dollars, and we can document the quality that you can provide.

Mr. Porter. You did make that an opportunity question. Good. [Laughter.]

Joe, thank you very much. We very much appreciate your testimony.

Dr. Cipfl. Thanks for your leadership, sir.

Mr. Porter. The subcommittee will stand in recess for the vote that is taking place on the House floor, and the period should be about 15 minutes.

[Recess.]

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness]

Wednesday, February 4, 1998.

WITNESS

WILLIAM H. MAHOOD, M.D., DIGESTIVE DISEASE NATIONAL COALITION

Mr. Porter. The subcommittee will come to order.

There's going to be another vote in probably 15 or 20 minutes, and we're going to try to get two witnesses in in that time, and I will try to keep quiet.

William H. Mahood, M.D., President, Digestive Disease National Coalition, testifying in behalf of the Coalition. Dr. Mahood.

Dr. Mahood. Mr. Chairman, thank you for the opportunity to appear before you today.

I am Bill Mahood, I'm a practicing gastroneurologist, just outside of Philadelphia, in a little place called Abingdon, Pennsylvania. I am the President of the Digestive Disease National Coalition.

We were founded in 1978, 22 professional and lay, that is patient-oriented, organizations. Mr. Chairman, the social and economic impact of digestive disease is enormous. Digestive disorders afflict approximately 62 million Americans, resulting in 50 million visits to physicians, 10 million hospitalizations, 230 million days of restricted activity, and nearly 200,000 deaths annually. The total costs associated with digestive disorders is estimated conservatively to be \$56 billion a year.

With these devastating numbers in mind, I would like to take the opportunity to thank you, Mr. Chairman, for what you have done in the past for the National Institutes of Health and for the Center for Disease Control and Prevention. Regarding the coming year, I would like to briefly discuss digestive disease research at NIDDK, colorectal cancer screening and prevention activities at the CDC, and hepatitis research and prevention.

Millions of Americans suffering from digestive disorders are pinning their hopes for a better life or even life itself on medical advances made through research supported by the NIDDK. Recent breakthroughs in the understanding of hemochromatosis, Crohn's disease, pancreatitis and other digestive abnormalities reinforce the need for continued support of NIDDK.

Where the fiscal year 1999, DDNC is recommending that the NIDDK receive a 15 percent increase over last year. This percentage translates into \$131 million over 1998. But at this point, Mr. Chairman, I would like to make clear that although DDNC strongly supports the concept of doubling NIH's overall budget in the next five years, we do not believe that these increases should come from the expense of other important public health service programs.

Now, colorectal cancer is the third most commonly diagnosed

cancer for both men and women in the United States. It's the second leading cause of cancer-related deaths. But we can prevent this cancer from killing by proper screening, and we can even cure it if caught early. Mr. Chairman, there's a tremendous need to inform the public about the availability and advisability of screening. We need to educate health care providers with respect to colorectal screening guidelines.

The recently initiated National Colorectal Cancer Screening Awareness program at CDC will address these needs. They are going to coordinate with national partners like our Coalition to develop an information program emphasizing the value of early detection. The digestive disease community hopes that this new program will do for colorectal cancer screening what CDC's breast and cervical cancer program has done for mammography and pap screening compliance.

Mr. Chairman, as the DDNC representative to the CDC colorectal screening program, I have seen first-hand the ambitious plan that CDC has to reduce the incidence of this devastating disease. As a result, we encourage the subcommittee to provide CDC with \$5 million, an increase of \$2.5 million over fiscal year 1998 for this vital and important campaign.

Finally, Mr. Chairman, I would like to talk about one of the country's most dangerous and prevalent infectious diseases, viral hepatitis. More than five million Americans are currently infected with chronic hepatitis B or C. Overall, 165,000 new cases a year. Because chronic viral hepatitis can result in liver failure, liver transplantation at a quarter of a million dollars a case often becomes the only treatment option available.

Already, chronic hepatitis C accounts for one-third of all liver transplants being performed in the United States. It's estimated that there are up to 10,000 deaths annually from hepatitis C. This number is projected to triple by the year 2010.

DDNC is pleased that the NIDDK convened a hepatitis C consensus development conference last March. We believe that priority should be given to supporting the research recommendations developed by the consensus panel, particularly the development of vaccines for hepatitis C, although we urge making existing hepatitis B vaccines available at at-risk populations through an expansion of the CDC vaccination program.

I appreciate the opportunity of being before you today, sir.

[The prepared statement of William H. Mahood, M.D., follows:]

[Pages 1626 - 1633--The official Committee record contains additional material here.]

Mr. Porter. Dr. Mahood, thank you very much for your excellent testimony. We will certainly take your views into account when we come to mark up the bill.

Thank you for being here.

Wednesday, February 4, 1998.

WITNESS

MYLES P. CUNNINGHAM, M.D., AMERICAN CANCER SOCIETY

Mr. Porter. Myles P. Cunningham, M.D., Immediate Past President, American Cancer Society, testifying in behalf of the Society. Dr. Cunningham, nice to see you.

Dr. Cunningham. Good afternoon, Mr. Chairman.

It is indeed a pleasure and an honor to come before this committee again. My name is Myles P. Cunningham. I'm a surgical oncologist from Evanston, Illinois, St. Francis Hospital. I'm here as the immediate past president of the American Cancer Society.

May I please begin with a comment on the new cancer initiatives proposed in the President's budget. The American Cancer Society supports all initiatives to increase cancer research and put cancer prevention into practice. However, the American Cancer Society believes that biomedical research, access to clinical trials and tobacco prevention and cessation programs must be considered and funded on their own merits and not be held hostage to the uncertain funding flowing from equally uncertain outcomes of tobacco legislation.

For the first time in history, we have witnessed a sustained decrease in cancer mortality and incidence. We know why this is so, and we know what we must do to accelerate this trend. While fewer people are dying overall, it is unfortunately not so true for the poor, the underserved, the minority Americans, who bear a disproportionate share of the cancer burden. Over and above all other funding priorities, we urge you to provide support for those activities, research, data collection, clinical interventions, that will let us serve those in greatest need.

Even if treatment for cancer were to become 100 percent successful, the simple fact is that most Americans would rather not develop cancer in the first place. We can prevent cancer. A mountain of epidemiological research has now persuaded us over the last 15 years that approximately 70 percent of cancer is preventable.

The impressive decline in lung cancer mortality recognized for the last five or six years is due simply to the fact that since the Surgeon General's tobacco report in 1964, you have been willing to fund tobacco cessation and avoidance programs that have worked. That includes programs for both cigarettes and smokeless tobacco.

This is the essence of cancer prevention, cancer prevention at its finest. More than any other single prevention initiative, we ask that you sustain and expand efforts to protect children from the lure of the deadly addiction of tobacco.

Mr. Chairman, 38 million Americans do not have a bad smoking habit. They are hopeless and craven addicts, addicted in their young teens and even earlier years, desperately trying to stop smoking and barely able to do so. Our government currently spends less than \$50 million annually on tobacco

control. This is less than the tobacco industry spends in just four days on promotions and advertising to expand their addict class and especially, regrettably, to seduce, to hook our kids.

Mr. Chairman, we need to improve our support for ASSIST and coordinated national programs in an amount not less than \$90 million, a mere pittance compared to the billions spent annually by the tobacco cartel. We must expand early detection and treatment access by increasing funding through signature public programs like CDC's breast, cervical and colorectal cancer initiatives. These are especially useful and warranted, because they target the underserved.

Thank you, Mr. Chairman, for the Medicare Benefits Improvement Act. I'm provoked in part by my colleague Dr. Mahood, I ask that, did you know that screening for colon cancer now covered for Medicare beneficiaries is also an extremely effective prevention tool, that if widely applied could theoretically eliminate colorectal cancer by identifying and treating precursor lesions.

Finally, Mr. Chairman, you are aware that the health care industry is now in the throes of blockbuster, mega merger deals. This industry is doing these deals because they, more than anyone, recognize the truly huge opportunities now available to eliminate human disease, especially cancer, through biomedical research. Biotechnology, molecular biology, gene research and all of the tools of modern scientific investigations, have brought us to the threshold truly of a revolution in modern scientific opportunity. We must seize this opportunity by substantially increasing our funding for cancer research.

We urge you to fulfill your commitment to a doubling of funds for both NIH and NCI.

Cancer mortality and incidents, as I have said, are now beginning to decrease. This is an unassailable fact and a sea change in the immunology of this terrifying disease. The American Cancer Society asks you to join us in our challenge to the American people to reduce cancer mortality by 50 percent by the year 2050. This goal is a stretch, it's a reach, but it's doable if we all get behind it.

We can meet this formidable goal only if we all do our part. Mr. Chairman, thank you for everything you've done in the past. Please continue to do your part for a healthy America.

[The prepared statement of Myles P. Cunningham, M.D., follows:]

[Pages 1636 - 1648--The official Committee record contains additional material here.]

Mr. Porter. Dr. Cunningham, I'll do my very best. We'll do our very best to meet the doubling goal that we've set. I don't know whether we're going to achieve it, or even a good start on it this coming year, but I have a very strong feeling that in the next year and the years after, that the chances will be quite good. It all depends on a very strongly growing economy. It's been doing wonderful, let's all keep it going that way. And we have a good chance of generating the resources we need

to do these things.

Thank you for appearing here this morning.

Wednesday, February 4, 1998.

WITNESS

MICHELE LICURSI, FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES

Mr. Porter. Next, we have Michele Licursi, Volunteer Regional Coordinator for FIRST's National Support Network, accompanied by her son, Ryan Licursi, testifying in behalf of the Foundation for Ichthyosis and Related Skin Types, which is FIRST.

Nice to see you. Thank you for being with us.

Ms. Licursi. Thank you. Mr. Chairman and members of the subcommittee, my name is Michele Licursi. I am testifying as a mother and a representative of the Foundation for Ichthyosis and Related Skin Types, which is FIRST. Testifying with me today is my son, Ryan. He has a type of ichthyosis called epidermolytic hyperkeratosis, or EHK.

I wish to thank the subcommittee for this opportunity to testify regarding funding for skin disease research and the budget for NIAMS. Ichthyosis is a family of genetic skin diseases characterized by dry, thickened, scaling skin. They are caused by genetic defects that are usually the result of genetic inheritance. There is no cure for ichthyosis and there are no truly effective treatments.

EHK causes the skin to be fragile. The slightest bump can cause the skin to break away. Blisters are common. Scaling and flaking are continuous. The skin is tight and cracks. The palms and soles are thick, making something as simple as holding a pencil or as natural as walking difficult and painful.

Overheating is dangerous, and infections are a constant threat. We're experts now, but 12 years ago, like most people, we had never even heard of ichthyosis. We learned together the hard way. We found out that diapers rubbed the skin off Ryan's leg, that car seats and high chairs had to be lined with sheepskin, that his daily skin care routine took several people and a couple of hours.

Relatives had to be taught how to pick him up and how to hold him. We no longer shopped for cute little outfits. We look for any clothes that his skin would tolerate.

Shoes were out of the question for years, and still continue to be a big problem. Ryan has been hospitalized for infections, simple medical procedures are complicated. Our days and activities are planned around his skin care. We get stares and question from strangers. We have been accused of all kinds of child abuse.

While the physical aspects of ichthyosis are obvious, the blows to one's self-esteem can be even more damaging. Ryan enjoys school, and has lots of good friends. But that's not the case with many kids with ichthyosis who are not as outgoing and confident as Ryan. Confident enough to tell you a little bit about living with ichthyosis.

Mr. Licursi. I'm 12 years old and in the seventh grade. As you know, I have epidermolytic hyperkeratosis, and it stinks.

There are many things that other kids can do that I cannot, because of my skin. It is very dry, fragile, and I blister very easily.

Any contact sport is out. I can't be on a basketball team, because if anyone bumps into me, or knocks me down, my skin will rip. I can't be on a soccer team, because if someone kicks me or I get hit with a ball, my skin will come off.

I often have blisters on my feet. I can hit the ball in baseball, but getting around the bases is another story. I'm always the last one picked for teams in gym class. In the winter, I even have trouble writing because the skin on my hands gets stiff and cracks.

Another problem with having EHK is that every day I have to get up an hour earlier than all the other kids in order to soak in the tub for half an hour, have cream put all over my body and let it soak in before I put on my clothes. If I didn't do this each day, I would be so stiff and dry that I could not stand it. It hurts to do it, but it would be worse if I didn't.

People in my town and school know me and understand my physical condition. When I go to the mall or any other public place, people stare and make comments. Any place I go, I leave a trail of skin. You will know I was sitting in this chair.

I would really appreciate any research that can be done to cure this condition.

Ms. Licursi. We recognize this subcommittee's strong history of bipartisan support for medical research funding and NIH. As a result, researchers have begun to identify the genetic mutations that cause EHK and several other forms of ichthyosis. We are excited about this progress and about the current research into gene therapy. We are hopeful about the possibility for an effective treatment or cure, but at this point, it's still hope. We continue to be frustrated by the lack of effective treatment options.

We're also discouraged by the lack of available testing facilities. Genetic testing is possible today for types of ichthyosis for which the specific mutations have already been identified. However, these tests are generally unavailable except on a research basis.

FIRST urges a 15 percent increase for NIH funding in the next fiscal year. FIRST also supports increased investment in translational research which would build upon this new scientific knowledge to develop practical applications for those with ichthyosis and other skin diseases.

In 1992, FIRST testified regarding the need for a national registry. Today, as a direct result of your interest and support, we have the national registry for ichthyosis and related disorders, which helps generate researcher interest in ichthyosis and provides investigators with a pool of affected individuals with a confirmed clinical diagnosis resulting in significant savings and research time and dollars.

Current funding for the registry expires in 1999, but its work must continue. Continued funding of skin disease registries will ensure these valuable resources will be maintained.

On behalf of our members, those with ichthyosis and their families, we thank this Congressional subcommittee for their time and attention.

[The prepared statement of Michele and Ryan Licursi follows:]

[Pages 1652 - 1657--The official Committee record contains additional material here.]

Mr. Porter. Ms. Licursi, thank you for your testimony.

Ryan, you seem to be doing real well. I think it's great that you're here to testify to bring the attention of the subcommittee to the disease that you suffer from, because you're going to help other kids, because we're going to find a way to unlock this key and make certain that this disease doesn't exist any more.

To the extent that we can provide the resources to scientists to do that, we are committed to doing just that. So we really appreciate your coming to testify. I think it helps a lot of other young people and others in your condition. I think it's terrific that you and your mom are here. Thanks so much.

Ms. Licursi. Thank you.

Mr. Porter. That obviously is another vote. We're going to try one more witness and see if we can get her testimony in before the bell rings again.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness]

Wednesday, February 4, 1998.

WITNESS

NANCY MUNRO, AMERICAN ASSOCIATION OF CRITICAL CARE NURSES

Mr. Porter. Nancy Munro, RN, MN, CCRN, ACNP, Critical Care Clinical Nurse Specialist, Georgetown University, testifying in behalf of the American Association of Critical Care Nurses.

Ms. Munro, you're going to have to explain afterwards the alphabet that is after your name.

Ms. Munro. I certainly will. I'm Nancy Munro, I'm a clinical specialist at Georgetown University Hospital. I'm pleased to be here to present testimony on behalf of the American Association of Clinical Care Nurses in support of funding for the National Institute of Nursing Research, the Agency of Health Care Policy and Research, and the Title VIII Health Professions program.

AACN is a not for profit association dedicated to the welfare of people experiencing critical illness or injury. AACN was founded in 1969, and has grown to be the world's largest specialty nursing organization, with nearly 73,000 members, representing the United States and 35 countries.

Our goal should be to translate the promise of scientific discovery into improved quality of life for all Americans. To accomplish this, we must continue to invest in medical research and the NIH. Towards this end, I encourage the subcommittee to support the recommendation of the Ad Hoc Group for Medical

Research Funding, which calls for a 15 percent increase in the NIH budget for fiscal year 1999.

It represents the first steps to double the NIH budget over the next five years. With that increased appropriation, AACN will work to ensure that NINR receives its fair share of the increase.

AACN strongly supports NINR's goals of health care effectiveness, cost effectiveness, and assuring that the scientific agenda has a humane aspect and translates research findings into applications that improve the Nation's health.

As nurses who provide care for the critically ill, one of the most important things we can do for our patients is provide relief for pain and suffering. Nursing affords a unique vantage point to examine which way pain affects patients and their families. Pain is a costly health care problem, prompting approximately 40 million visits to health care providers each year, and over \$100 billion annually in lost productivity and health care expenses.

Over the past year, NINR has reported two groundbreaking advances in pain research, one showing gender differences in response to analgesics, and the second indicating that sedatives given before surgery can actually block the action of medication given to relieve pain after surgery.

AACN currently sponsors Thunder Two project, a large multi-site research partnership project in partnership with several other nursing organizations. The purpose of this research is to examine pain perceptions and responses in critically and acutely ill pediatric and adult patients in selected procedures. Data collection is underway and hopefully will be completed by 1999. To date, over 200 sites are enrolled in the United States, Canada, Australia and United Kingdom.

AACN also supports NINR's leadership in improving end of life care. NINR recently held a state of the science conference on symptoms of terminal illness, to address end of life issues in four areas: pain, dyspnea, cognitive differences and cachexia. AACN firmly believes research is needed to develop a scientific basis for critical care nursing practice to achieve a broad understanding of the role and impact of critical care nurses on patient outcomes.

Many research projects funded by the AHCPR are gradually helping communities to refocus health care so it is truly driven by the needs of patients and their families. AACN was pleased to see that the patient budget includes \$171 million for AHCPR and a \$25 million increase over 1998.

As you know, in 1990, Congress passed the Patient Self-Determination Act, which AACN believes has made significant progress in educating Americans about their right to make their own health care decisions. This is of particular interest to AACN in light of the Robert Wood Johnson study that followed 9,000 critically ill patients, and found discrepancies between the patients' end of life decisions and their actual treatment.

AACN currently is working to educate consumers about the Patient Self-Determination Act and its importance. Committee support for AHCPR has provided AACN with the resources to design a community outreach program to improve completion rates for advance directives. AACN's program, in conjunction with UCSF research on advance care planning, including advance

directives, has specific emphasis on education, stressing definition and documentation of patient preferences, so in the event of a catastrophic event, the individual preferences can be honored.

Additional funds were also received for the project as a result of AHCPR funding in 1998. AACN believes that education is fundamental for professional growth, and to the excellence in clinical practice and optimal patient outcomes. Practitioners must confirm to a lifelong learning to assure that they remain competent, fulfilling their obligations to patients and the families that they serve.

According to the Bureau of Labor Statistics, the demand for health care professions is expected to grow to 47 percent by the year 2005, with the need for advance practice nurses among the greatest. In addition, an Institute of Medicine study on the role of nursing staff in hospitals found that more advanced or more broadly trained registered nurse work force would be needed in the future. Such training is currently funded under programs funded under Title VIII of the Public Health Service.

AACN is pleased that Congress has provided an increase in health professions training, and hopes it will again demonstrate support in 1999.

In closing, thank you, Mr. Chairman, for this opportunity and your support of nursing research in the NIH.

[The prepared statement of Nancy Munro follows:]

[Pages 1661 - 1674--The official Committee record contains additional material here.]

Mr. Porter. That was perfect, Ms. Munro, thank you.

I have an RN in mind and CCRN I assume is critical care?

Ms. Munro. That's a certification by AACN.

Mr. Porter. What's MN?

Ms. Munro. Masters in Nursing.

Mr. Porter. ACNP?

Ms. Munro. I'm proud to say that I just completed my Acute Care Nurse Practitioner certification.

Mr. Porter. Okay. Just for my education.

Obviously, we are listening very intently to what you say, and we agree with you that a lot of progress has been made at the National Institute of Nursing Research. We want to be supportive and we really thank you for coming here to testify in their behalf today.

Ms. Munro. We appreciate it.

Mr. Porter. Also I might add, health professions is a high priority. Mr. Bonilla has been one of our leaders on this. I think he will tell you as well, that it would be helpful if the word got over to our colleagues on the other side of the rotunda that this is a very high priority, too.

Ms. Munro. We're definitely trying.

Mr. Porter. Thank you, Ms. Munro.

The subcommittee will stand in recess until these votes have been completed.

[Recess.]

Wednesday, February 4, 1998.

WITNESS

DONNA A. MELTZER, FRIENDS OF NICHD COALITION

Mr. Porter. The subcommittee will come to order.

Our next witness is Donna A. Meltzer, Chair, Friends of NICHD Coalition, and testifying in behalf of the Coalition.

Ms. Meltzer. Thank you, Mr. Chairman.

I'm pleased to be able to testify today on behalf of the Friends of NICHD Coalition, a coalition of nearly 100 organizations that support the extraordinary work of the National Institutes of Health, with a special focus on the National Institute of Child Health and Human Development.

Our coalition, which is in its twelfth year, includes scientists, health professionals and advocates for the health and welfare of women, children, families and people with disabilities.

A recent quote I saw in a Washington Post article said, I will protect my child from everything except a life lived passionately. I noted this quote, as it seemed to summarize exactly the way my husband and I hope to raise our children. While I can encourage my young son to live passionately, the opportunity to do so will ultimately be his.

However, as a parent, it is my job to protect his health and nurture his well-being in every way possible. Thanks to the work of the NICHD, many parents, including myself, have been able to deliver healthy babies and do a better job of protecting them. With testing such as that for PKU, a test which was developed by NICHD, parents are able to prevent, to the best of our ability, the occurrence of mental retardation in our babies. We now know that we must put our babies to sleep on their backs to prevent SIDS, and we working moms can feel better about having our children in day care, thanks to the information that NICHD has been collecting in the ongoing child care study.

I'm especially pleased today to be able to thank you for your strong support for NIH. In spite of the recent tight budgets, you have held fast to your belief in investing in America's health. You have turned to us, the Friends of the NICHD, to help share knowledge about NICHD's work with you and your staff.

Last winter, we were able to bring nearly 50 appropriations staffers to the Bethesda campus, where they were able to see first-hand what it's like to be both a patient at NIH as well as lab researcher. It is our hope to expand that knowledge to all members of Congress and their staff in June, when the Friends of NICHD will host, as part of NICHD's 35th anniversary year, a scientific exhibition and reception.

It is unbelievable to all of us to think that just two short years ago we had a budget deficit of \$292 billion. Now in 1998, we are hearing a different and exciting word: budget surplus. Whether or not a surplus can be made available for use, the Friends of NICHD would like to see surplus equal solutions. For 35 years, the NICHD has been providing solutions through research, solutions for the world, the Nation, and the

families that live in your town.

Solutions such as prevention of premature delivery. NICHD researchers have found that not only can maternal infection cause amniotic infection, but that the actual premature delivery can be stimulated by the fetus attempting to escape a dangerous uterine environment in order to protect itself. However, the resulting premature birth may pose an even greater risk to the fetus.

Therefore, NICHD is developing a rapid method for detecting infection, allowing clinicians to intervene with antibiotics more quickly, and to help eliminate the infection causing the premature birth.

As you well know, NICHD is home to the Back to Sleep campaign. I am thrilled to tell you today that the latest statistics show that SIDS deaths have been reduced nationwide by 38 percent and brand new data just in from the State of California shows a 50 percent decline in SIDS-related death.

Another public information campaign is finding solutions for osteoporosis and bone density loss. The milk mustache campaign, targeted especially at getting young women to drink milk, is effectively using the media to get across the important message that calcium is critical for a healthy adult body, and that drinking milk can still be cool.

NICHD is funding solutions for genetic and related disorders like fragile X syndrome, Rett syndrome, Downs syndrome and others. NICHD research has linked specific errors on human chromosome 15 to highly specific behavioral disorders of major health importance. This information can lead not only to cures for the syndrome, but other abnormalities that often accompany the syndrome.

Mr. Chairman, these are but a few examples of solutions being created through NICHD research. On behalf of the Friends Coalition, I urge you to continue your support for more advances yet to come and recommend that the NICHD receive \$776 million in funding for fiscal year 1999, a 15 percent increase. Our recommendation is commensurate with the request of the Ad Hoc Group for Medical Research Funding.

In 1961, President Kennedy said, we have conquered the atom, but we have not yet begun to make a major assault in the mysteries of the human mind. With your continued support, we can make a major assault on those mysteries. We thank you for your leadership, which offers healthier futures for all of our children.

Thank you.

[The prepared statement of Donna Meltzer follows:]

[Pages 1678 - 1686--The official Committee record contains additional material here.]

Mr. Porter. Thank you very much for your good testimony, Ms. Meltzer. Obviously we think very highly of Dr. Dwayne Alexander and NICHD. It's wonderful they have friends like you. Thank you for being here to testify.

Ms. Meltzer. Thank you very much.

Wednesday, February 4, 1998.

WITNESSES

SUSAN SANABRIA

CAROL DOWNING, NATIONAL MULTIPLE SCLEROSIS SOCIETY

Mr. Porter. Susan Sanabria, Vice President, Advocacy Programs Department, National Multiple Sclerosis Society, accompanied by Carol Downing, Maryland Chapter Representative, of the Society, testifying in behalf of the Society.

Susan, it's wonderful to see you.

Ms. Sanabria. As it is to see you, my former boss.

Mr. Porter. Right. Susan used to be on my staff. Don't remind me--well, do remind me of the dates.

Ms. Sanabria. When you first elected, 1980 to 1981.

Mr. Porter. Just a short time ago.

Ms. Sanabria. You look wonderful.

Mr. Porter. So do you.

Ms. Sanabria. I'm very grateful for the opportunity to come and talk with you about funding for the agencies that are near and dear to our heart. The National Institutes of Health, and within the Department of Education, the Rehabilitative Services Administration and the National Institute for Disability Research.

With me today is Carol Downing, from our Maryland Chapter, who will be presenting our testimony.

Ms. Downing. Thank you, Mr. Chairman.

I appreciate the opportunity to be here today to speak to you on behalf of the National Multiple Sclerosis Society, which is an organization that directly supports biomedical research and provides services through its chapters across the country to a third of a million people with multiple sclerosis and their families.

Let me briefly tell you my story. I was diagnosed with MS in 1984. At that time, I was a single mother, just laid off from my job as a paralegal and benefits specialist, and not surprisingly, under great stress. I was hospitalized for MS many times, and I was in a wheelchair for two and a half years. I'm now able to use canes or a walker, the mobility impairments are still part of my daily routine.

My close relationship with the Maryland chapter of the MS Society began when I discovered that my home of 20 years was no longer accessible. Staff at the chapter worked with my family to make our new apartment accessible. I'm not a disability and research advocate for the Society. My chapter serves at least 3,500 people and their families throughout the State.

The chapter raises money for private biomedical research contributing to the National MS Society's \$18 million research budget. As a national research associate at the Maryland chapter, I keep up with research trends at both the society and at NIH as well as rehabilitation research at the Department of Education.

MS is a progressive, degenerative disease of the central nervous system, unpredictable in its course and devastating in its impact, since it can cause spasticity, tremors, abnormal fatigue, bladder and bowel dysfunction, visual problems and

mobility impairment. The disease usually strikes between the ages of 20 and 40, just as a career and family life begins and develops.

Ending the devastating effects of this cruel disease depends on the discovery of a cure or new therapies to control, treat and eventually halt its progression. I have participated in a number of clinical studies to evaluate new treatments for MS. Recently, an FDA advisory panel approved three new drugs, Avenex, Betaserin and Copaxone. These injectable drugs have shown positive therapeutic effects on the underlying disease in some people.

Building on essential basic and clinical research, scientists have made these and other significant strides in removing the mystery from this unpredictable, destructive disease. We must greatly enhance this progress, as I continue to hope that the research I'm asking you to fund today will improve my life and those of others living with MS.

The mission of the National MS Society is to end the devastating effects of MS. You have the ability to advance this admirable cause by significantly increasing funding for research projects and centers at both the NIH and the Department of Education on rehabilitation.

The National Multiple Sclerosis Society believes that the following appropriations are needed in order to take advantage of current opportunities in biomedical and rehabilitation research. First, a 15 percent increase for the National Institute of Neurological Disorders and Stroke, where research on the nervous system and the brain takes place.

You may have read in the New York Times last Wednesday about a study that further delineates what happens to the nervous system of people with MS. The more we know about the disease, the more we can target treatments for early intervention.

Second, a 15 percent increase for the National Institute of Allergy and Infectious Diseases. MS is an autoimmune disease. The results of several important studies at the NIAID are leading new possibilities for MS treatments as well as knowledge about genetic susceptibility.

Third, a 15 percent increase for all of NIH, including the Center for Medical Rehabilitation Research. Concerning the NIH budget as a whole, we at the Society certainly support the popular idea of doubling the NIH budget in five years. There are many fruitful lines of research to pursue.

Finally, we ask for a 7 percent increase for the Rehabilitation Services Administration and for the National Institute of Disability and Rehabilitation Research within the Department of Education. With additional funds, we could enlarge studies such as the following, the effects of Betaserin have now been studied in a group of subjects with early, mild, relapsing, remitting MS to test the drug's ability to reduce breakdown of the blood-brain barrier. In those studies, all have had dramatic reduction in lesions with complete cessation of disease activity as measured by MRI.

These findings suggest an important site of action for beta interferons. The studies also provide further evidence of the usefulness of MRI. Studies such as these are the foundation for more research if there were more resources.

On behalf of the National Multiple Sclerosis Society, let me echo what others have stated at these hearings. Let research move forward at a rapid pace.

Thank you very much.

[The prepared statement of Carol Downing follows:]

[Pages 1690 - 1695--The official Committee record contains additional material here.]

Mr. Porter. Sue, I can't remember whether Don Grossman was our campaign treasurer at the time you were on staff, but his wife, Susan, contracted MS probably about 10 or 12 years ago. She had always been a very active athlete, she was a championship golfer. It's just been devastating to her and to her family.

So I've had an up-close look at the effects of this disease on someone I know very, very well. Believe me, we want to do everything we possibly can to get the resources to the research scientists who can help.

We very much appreciate your coming to testify today, Susan and Carol both. We'll do our very best to try to reach those goals and at least give us a hand with the budget people.

Ms. Downing. Thank you very much.

Ms. Sanabria. We promise we will.

John, if I may speak as a member of your staff, past and present, you've done us proud.

Mr. Porter. You're very kind to say that, Sue. I've had a wonderful staff all these years, too.

Thank you.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

Wednesday, February 4, 1998.

WITNESS

MIRIAM SCHNEIDMILL, NATIONAL PEMPHIGUS FOUNDATION

Mr. Porter. Miriam Schneidmill, Member, Board of Directors, The National Pemphigus Foundation, testifying in behalf of the Foundation. Welcome.

Ms. Schneidmill. Good afternoon, members of the subcommittee.

My name is Miriam Schneidmill. Before I begin my testimony, I would like to thank you, especially Chairman Porter, for your strong support of the NIH. I am here today as a representative of the National Pemphigus Foundation. The National Pemphigus Foundation joins with the Ad Hoc Group for Medical Research Funding, the National Institute of Arthritis, Musculoskeletal and Skin Diseases, and the Coalition of Patient Advocates for Skin Disease Research in asking for a 15 percent increase in the budget of the NIH.

In 1992, I was diagnosed with pemphigus vulgaris, PV. PV is

one of a group of blistering skin conditions which includes pemphigus foliaceus and bullous pemphigoid, among others. The National Pemphigus Foundation has been established to encourage communication about, and research into, these blistering diseases.

Pemphigus vulgaris is a rare autoimmune disease--I am allergic to my skin. People with PV form blisters on their skin and mucous membranes. These become sores, lesions, erosions that do not heal. Without treatment, the patient suffers the fate of a burn victim, infection, shock, and ultimately death.

Before the discovery of the glucocorticosteroids, PV was 100 percent fatal. Today prednisone, a glucocorticosteroid, remains the effective known treatment. However, prednisone has many devastating side effects. It is associated with osteoporosis, diabetes, cataracts, myopathy, mood swings, and even psychosis. The adjuvant treatments, often from the chemotherapy shelf, like Cytosan, Methotrexate, and Imuran are associated with liver damage and a greater incidence of cancer.

It took more than 12 months for my diagnosis of PV. I went from doctor to doctor and was treated for folliculitis, herpes and yeast before someone finally biopsied the lesion on my scalp and discovered it was PV. The delay, in my case, was due to the mild presentation the disease was making. For those with a few lesions in their mouths followed by extensive skin involvement, the diagnosis is much quicker, but they are much more ill than I was.

However, the treatment is basically the same for all of us, high doses of prednisone. I have been on three courses of high dose steroids. Each time, I immediately develop side effects. My face became round, I gained weight, my muscles became weakened. I was unable to walk more than one block. I was fortunate, my friend David, 18 when diagnosed, couldn't walk at all. My friend Stephanie died of the complications of treatment at age 22.

Although I am only 48 years old, I have an incipient cataract and osteoporosis. I am at risk for spontaneous fractures to my spine. My friend Hannah Lisa suffered such a fracture less than six months after a bone density scan that showed her spine to be above average. As a result, she is in constant pain and has lost two inches of height.

I am here today to talk about what we need and what people with other rare diseases need: research. First, we need basic research. Today we know that in pemphigus, patients produce auto-antibodies to the desmosomal proteins of the skin. These proteins are what hold the skin together.

However, there is much we do not know. We do not know how or why these antibodies form. We also do not know the role that environmental factors such as viruses, bacteria, allergens and toxins play in this disease.

Second, we need clinical research. I believe that the NIH needs to fund more clinical research, because funds from the traditional sources are drying up. In the past, clinical research was supported not by the pharmaceutical companies or the NIH, but by the academic health centers, AHC. Income from patient care was used by the AHC to support clinical research.

Now, the research function of the AHC is in danger because of the low rates of payment made to hospitals by managed care

organizations. The result of the lower rates is that the young clinical investigator is forced to see more patients, so that there is neither time nor money for clinical research.

I am here today to tell you that a better, less life threatening treatment for pemphigus can only be discovered by continuing to support the basic research mission of the NIH, and by encouraging greater support for clinical research. The money you make available for research is holding my skin together. I hope that for these reasons you will support a 15 percent increase in the NIH budget.

[The prepared statement of Miriam Schneidmill follows:]

[Pages 1699 - 1701--The official Committee record contains additional material here.]

Mr. Porter. We are going to do our best, Ms. Schneidmill. I have to say, I'm not personally familiar with PV, but I am very familiar with the effects of high doses of prednisone and the side effects that that can cause. There's got to be a better way to treat this disease. It's a powerful drug that can have its own effects on your health in other ways.

So believe me, we'll do our best. Thank you for coming here to testify.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

Wednesday, February 4, 1998.

WITNESS

W. BRUCE FYE, M.D., AMERICAN COLLEGE OF CARDIOLOGY

Mr. Porter. W. Bruce Fye, M.D., FACC, Chairman of the American College of Cardiology's Government Relations Committee, testifying in behalf of the College.

Dr. Fye. Mr. Chairman, I am Bruce Fye, Chair of the Government Relations Committee of the American College of Cardiology, a 24,000 member professional society and teaching institution. I also chair the cardiology department at Marshfield Clinic, a 525 physician group practice in Wisconsin.

I am here today on behalf of the American College of Cardiology to ask you to renew your major commitment to the National Heart, Lung and Blood Institute. As the college's official historian and the author of a recent book on the history of American cardiology, I am especially pleased to have this opportunity to speak in support the Institute on its 50th anniversary.

The first Congressional appropriation to NHLBI was just \$500,000. Since then, thanks to this subcommittee's consistent support, the Institute's budget has grown to \$1.5 billion. Happily, as a result of this Nation's investment in biomedical research, the prospects for combatting the catastrophic consequences of cardiovascular disease are better than ever.

There is much to be done, however.

Today, heart disease claims more lives than any other illness. This year alone, one million Americans will die as a result of cardiovascular disease. More than 50 million Americans, about one-fifth of the population, are living with some form of cardiovascular disease.

Fortunately, most of them are living better and longer lives, and more productive lives, as a result of new drug and device therapies, surgical innovations, enhanced emphasis on prevention, and innovative public educational programs, all made possible through NHLBI-funded research.

Our citizens, many of them potential cardiac patients, do not want us to become complacent as we celebrate the many advances in the prevention, diagnosis and treatment of cardiovascular disease that have resulted from our Nation's pioneering research and educational programs. The main goal of investing in cardiovascular research is to prevent premature death and improve the quality of peoples' lives. We also want to control the enormous social and economic burden of cardiovascular disease.

In 1998, the total economic impact of heart disease in the United States is projected to reach \$175 billion if lost productivity is factored into the equation. Medicare paid about \$29 billion for the treatment of heart disease in 1995 alone.

Research is a major tool to help us cut these costs. Think of the impact that research had on tuberculosis and polio. Major public health problems just a few decades ago.

In this extraordinary era of molecular biology, NHLBI funded researchers are on the brink of making many major discoveries that should yield significant cost savings in the area of cardiovascular disease. Exciting new discoveries by NHLBI funded researchers are already having a major impact on heart care.

For example, we know from a recent clinical trial that the risk of developing heart failure can be cut in half in older persons with hypertension if they are treated with a low dose diuretic. The benefits are even greater in patients who have had a heart attack.

Heart failure is regrettably a common and very serious problem that we must work harder to prevent. Because there are more than 400,000 new cases of heart failure annually in this country, the potential benefits from this type of research could be enormous.

Innovative research in human genetics and molecular biology holds great promise for the prevention and early diagnosis of cardiovascular disease. We are just beginning to realize the remarkable potential of this fertile area of research. For example, NHLBI-funded investigators recently identified a genetic marker for one cause of hypertension. Like other genetic markers for diseases that are preventable or treatable, this holds great promise for reducing the impact of hypertension and its serious consequences.

Early reports from NHLBI-funded researchers working on gene transfer techniques and cardiovascular disease are equally promising. Preliminary findings suggest that this innovative approach might slow the development of atherosclerosis in vascular grafts such as those used in coronary artery bypass

surgery. Other studies suggest that it may be possible to promote recovery of cardiac function after a myocardial infarction by introducing healthy heart cells into weakened heart muscle.

By continuing this Nation's major investment in biomedical research in general and NHLBI-sponsored research in particular, Congress will help literally thousands of investigators make discoveries and advance knowledge. As researchers open new paths to and through medical frontiers, it is exciting to contemplate the implications for the future health of our citizens. Already, as a result of a multitude of discoveries and innovations, thousands of highly skilled cardiovascular specialists are performing procedures such as coronary angioplasty and prescribing medical treatments that were unimaginable just a few short years ago.

This is not just about treatment. Health care professionals are also promoting powerful prevention strategies that have been validated by NHLBI-sponsored researchers. This year the Institute will convene a special panel that will help develop recommendations for the more rapid dissemination of research findings that speak to the important issues of prevention and the effective treatment of cardiovascular disease.

The need to reduce the enormous social and economic costs of cardiovascular disease is a compelling reason to increase the NHLBI budget significantly. The need has never been greater. The United States must prepare itself, both scientifically and fiscally, for the inevitable increase in the incidence of cardiovascular disease that will accompany the graying of the so-called baby boomers generation.

I hope the subcommittee shares my optimism about the unique opportunities that our scientists and clinical investigators now have to achieve their longstanding goal of conquering this Nation's number one killer. In summary, the American College of Cardiology would like to encourage you to continue to generously fund the National Heart, Lung and Blood Institute. It is a wise investment in our Nation's future.

Mr. Chairman, I deeply appreciate having this opportunity to testify before the subcommittee.

[The prepared statement of W. Bruce Fye, M.D., follows:]

[Pages 1705 - 1714--The official Committee record contains additional material here.]

Mr. Porter. Dr. Fye, thank you for your very good testimony. I have to say that, I think we've said this this morning, sometimes we see so many panels that I don't know what I've said to them, but we have historically, you mentioned NHLBI increasing from \$500,000 to \$1.5 billion, if you look over the history of the funding of NIH, it has increased on average about 3 percent in real terms each year above inflation.

The problem in not being able to fund worthy science is not that we haven't increased funding for NIH. We've done that. But science has increased the opportunities and the quality of the research available to fund faster than we've generated funds to

keep up with it.

That's exactly the reason why we have to look at a goal of very rapidly increasing overall funding for NIH, because we're falling behind the curve of scientific opportunity that's available to us. In the process, of course, discouraging a lot of young investigators who otherwise would be excited to stay in the field if they had an opportunity to see the research that they have proposed being funded.

We're going to do our best to meet that challenge. It's a very real and very important challenge. One of the previous witnesses had mentioned, and you had mentioned, clinical research that we also think is under a great deal of siege by reason of the reorganization of our health care delivery systems in the country. In a way, it isn't the primary responsibility of this subcommittee. But it's certainly a great concern of the subcommittee that many of our academic medical centers are finding themselves really squeezed by the lack of revenues that used to be there under our previous system of providing payment for public programs.

So these are real challenges and we're going to do the best that we can to meet them. Thank you for testifying.

Dr. Fye. Thank you very much.

Wednesday, February 4, 1998.

WITNESSES

DOUGLAS A. JOHNSON, CENTER FOR VICTIMS OF TORTURE
MANOUCHEHR DUSTI

Mr. Porter. I'm going to ask Dr. Bisgard if, Mr. Johnson, who is witness number 14 on the list, has advised us that he has a plane to catch. Is that a problem? Not a problem. Thank you very much, sir.

Douglas A. Johnson, Executive Director of the Center for Victims of Torture, accompanied by Manouchehr Dusti, torture survivor, small business owner, testifying in behalf of the Center for Victims of Torture.

Mr. Johnson.

Mr. Johnson. Thank you, Mr. Porter. Thank you for the opportunity to discuss the importance of providing rehabilitation services for victims of torture. I wish I had time instead to hear about Turkey and your trip, but perhaps at another point.

We're referring to people now residing in the United States who were tortured by foreign governments, although we would include many Americans who we've seen at the center who were also tortured abroad. We estimate there are between 300,000 and 400,000 survivors of government-sponsored torture now residing in the United States.

One of those is Mr. Manouchehr Dusti, of Iran, who's here with me today. Besides the very difficult but common challenge that he and other refugees have of adjusting to a new culture and language in exile, torture survivors must also cope with physical pain and often very debilitating emotional impacts of torture. Nightmares and flashbacks, anxiety disorders, depression, post-traumatic stress disorder, these symptoms can

adversely affect their relationships with their family, their community, and their ability to secure employment.

These are profound humanitarian issues which should be of concern to us. But there are other important reasons for us to care about this population. Torture victims are largely targeted because they were leaders in their communities, that their governments decided to fear what they were doing, what they thought about. They were often in the forefront of a struggle for democracy and human rights in their societies, some were opposition party leaders, others were leaders in human rights, workers rights, religious freedom, the media.

The Center recently concluded a five year retrospective study for the National Institute of Mental Health. Those findings underscore the previous leadership role that torture survivors filled in their societies. Over 50 percent of our clients, for example, had college degrees. Twenty percent had graduate professional degrees. They had major areas of responsibility in their countries. Their societies had often invested heavily in them, in their education and in their experience before the government decided that they were dangerous to the government.

Nearly all of our clients defined one aspect of their healing as becoming self-sufficient again, of taking care of their families, of making contributions to their community. They've had a taste of success and of making a difference. But they're now hampered by the symptoms of torture.

We propose that this means helping survivors of torture is also a very good investment for our communities and our Nation. They are both highly educated and very highly motivated to make a valuable contribution to our society, as demonstrated by our clients over and over again. They are now in our communities, our neighbors, they're our people, and our people will benefit by restoring their health and recovering their leadership.

There are many other things to be said in our discussion, which I will simply leave in the written testimony in order to give Mr. Dusti an opportunity to speak about his experience. In the past, the appropriations committee has urged ORR to become involved in this issue. ORR has issued a very small funding request for training. But it has not taken any leadership in providing funding for services.

There are now 15 treatment centers around the United States who are providing care for victims of torture. They are all doing so without any funding of any support from either their State or Federal Governments, and largely are not supported by the foundation community, which considers torture and treatment to be an operating cost as opposed to a new initiative that they would support.

It is our hope that you will pursue the issue with ORR in its future testimony about how they can fulfill the mandates that you've laid out for them before. It's also our hope that you will earmark funding within HHS that will support direct treatment services for victims of torture, to help this community recover and also for the U.S. to meet its obligations under the convention against torture.

I'd like to introduce Mr. Dusti, who was a business leader in Iran, but became very active in the opposition to Khomeini's regime.

Mr. Dusti. Good afternoon, Mr. Chairman.

My name is Manoucher Dusti. I came from Iran in 1988 to the United States.

I have been imprisoned and tortured by my government. I have been in business long enough, but because of my activity against the government, my government, I involved and went to prison and torturing.

When I got to the United States, at Hambling University, I had a lot of trouble. The government seized all my assets, all my money, everything is gone. Suddenly, I found myself homeless, hopeless, like a lot of unknown people who have been doing lots of things, but in the same situation, going to bed without anyone knowing. That's tough.

We work all our life, but no one can bring our mind down. I find myself in the United States, in the safest country on the earth, lonely, homeless and miserable. Some people referred me to the Center for Victims of Torture. During a three to four years period, I got back on my feet again. I worked hard.

They gave me hope, trust, how to get back with my life without being scared, without nightmares, without lots of problems day and night. During the day, I am scared all the time, thinking someone will catch me during the night, I get nightmares of how they tried to execute me. I wish they did, but they never done it. All these things are with me every day.

Now I'm in the position to control those things. Thanks to the Center for Victims of Torture, I believe there are lots of people like me around this corner of Washington. Lots of people need help. There is no, we need lots of things to get back to community and health.

I am married, I have a beautiful son, and I employ 50, 60 people now. I have two, three business, from homeless in five years, six, got back to business, and giving back to my community. This is the place my son is being raised. I hope my son one day be like you to help in the community, helping the people.

I take this moment and say it, lots of people are dying without anyone knows. They are unknown heroes. If someone is executed, something happens, everybody knows it, everybody says it. But some people have been tortured and no one knows. They go in the darkness and kill themselves, because there is no hope in that moment. And it is tough, very tough.

I believe we need lots of centers around this United States. There are lots of people coming down here, this is land of opportunity. This is the promised land to us, land of freedom. We need that.

Thank you.

[The prepared statement of Douglas Johnson follows:]

[Pages 1719 - 1722--The official Committee record contains additional material here.]

Mr. Porter. Mr. Dusti, thank you for reminding us. I have to say that Doug Johnson does some wonderful work, and we want to be as supportive as we possibly can of his efforts. You've highlighted for us the needs of people like yourself who have

gone through what you've gone through.

We'll do our very best to be responsive. Thank you.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

Wednesday, February 4, 1998.

WITNESSES

GERALD BISGARD

GALE DAVY, WISCONSIN ASSOCIATION FOR BIOMEDICAL RESEARCH AND EDUCATION

Mr. Porter. Gerald Bisgard, Ph.D., President, Wisconsin Association for Biomedical Research and Education, Department of Comparative Biosciences, University of Wisconsin, School of Veterinary Medicine, accompanied by Gale Davy, Executive Director, Wisconsin Association for Biomedical Research and Education, both testifying in behalf of the Association.

Dr. Bisgard.

Dr. Bisgard. Chairman Porter, we thank you for the opportunity to testify today.

I'm Gerry Bisgard, President of WABRE, Wisconsin Association for Biomedical Research and Education, and professor of comparative biosciences at the University of Wisconsin-Madison.

WABRE is a non-profit educational organization. Our mission is to provide public education on scientific issues to the citizens of Wisconsin. The Association is supported by the State's academic research institutions, hospitals and clinics, bioscience businesses, and community organizations concerned with public health.

Wisconsin scientists have contributed immensely to our Nation's public health and scientific knowledge. They are helping to map the human genome, creating new drugs and prevention therapies for breast cancer, hypertension, coronary artery diseases, farmer's lung disease, developing new vaccines, developing new techniques for blood transfusions and safer anesthetics.

It should also be mentioned that the drug coumadin, which one of our previous testifiers was taking, Dr. Greenberg, was discovered at the University of Wisconsin.

My research focuses on the studies of respiratory illness. The University of Wisconsin is one of the leading state universities for biomedical research in the Nation. However, research is no longer the exclusive purview of academic centers in Wisconsin. One of the largest centers for epidemiological studies in the world is found in the small town of Marshfield, Wisconsin, home of the Marshfield Medical Research Foundation, and the National Farm Medicine Center.

In Wausau, the non-profit CARE Foundation is building on research conducted nationwide by expanding clinical research to the residents of this small city and surrounding communities. For medical school clinics in the central city of Milwaukee to a small hospital in the north woods of Rhinelander, more Wisconsin patients are receiving the benefits of medical

research.

Wisconsin scientists, like scientists throughout our Nation, are working diligently in the public interest. But all scientists are having a difficult time securing funding for this valuable research.

We support the proposal of the Ad Hoc Group for Medical Research Funding, which calls for a 15 percent increase in funding for the NIH in fiscal year 1999 as a first step towards doubling the NIH budget over the next five years.

We recognize the difficulty in achieving this goal under current spending limits. We don't envy your job. But we ask that all members of Congress explore all possible options to identify ways to provide the additional resources needed to support this increase.

We recognize the Congress and this committee have been supportive of research in the past, and we thank you very much for that support. You should know that the public is supportive of your efforts as well. A statewide poll commissioned last year by Research! America showed that 60 percent of Wisconsin residents favored doubling our national spending on medical research by the year 2002. Similar polls in Alaska, California, Florida, Louisiana, Ohio, Pennsylvania and Texas show similar results.

Medical research is so valuable to our public health, medical education, controlling health care costs and work force productivity that it provides a remarkable return on our public investment. WABRE has recently carried out an analysis of this public investment in biomedical research. This study showed that Americans earned \$81 for every dollar spent on medical research and development in direct and indirect economic benefit, an incredible return on investment.

How much would we invest? Studies comparing various rates of investment in biomedical research since 1950 show that the rate of return remains relatively constant, regardless of the investment. In other words, over the course of nearly 50 years, we have not yet approached a maximum investment ratio where the rate of return begins to decline relative to the value of that investment.

If we increase our investment, we will reap strong health and economic return on the investment. That much is not in question. What is in question is, how much can we afford to invest. That is the question you in Congress must answer.

Chairman Porter, the last three post-doctoral fellows trained in my laboratory to pursue careers in academic research have elected alternate careers because they see other young researchers failing to obtain funding. And they see senior researchers losing funding.

Increasing the NIH budget will greatly increase our ability to keep talented young scientists working where their hearts are, in biomedical research in the public interest. On behalf of active researchers like me, on behalf of young scientists who would like the opportunity to serve the public, and on behalf of the people of the State of Wisconsin, WABRE asks your support for a 15 percent increase in funding for the NIH.

Thank you very much.

[The prepared statement of Gerald Bisgard follows:]

Mr. Porter. Dr. Bisgard, thank you for your testimony.

Am I correct that Dr. Fye, who testified before you, is also from Marshfield?

Dr. Bisgard. We are not from Marshfield, but we were delighted to hear that somebody else from Wisconsin was here. Gale said she recognized his name but didn't know him.

Mr. Porter. When you mentioned Marshfield in your testimony, I had noticed in his curriculum vitae that he was from Marshfield. He's at the Marshfield Clinic.

Dr. Bisgard. Marshfield is a center of excellence in medicine, which is surprising for such a small city.

Mr. Porter. He lives in Marshfield. I assume that's near Madison?

Dr. Bisgard. No, that's 100 miles or so.

Ms. Davy. Actually, Marshfield has a very interesting story. It was basically founded as a clinic, a rural clinic. It's actually in central Wisconsin near the city of Wausau. It has just developed an excellent research program. It's actually the third largest research center in the State of Wisconsin right now, but it's not an academic research center. It's affiliated with the clinic and the hospital.

Mr. Porter. It just happened that you were talking about Wisconsin, you mentioned Marshfield, he came from Marshfield and you didn't know one another?

Dr. Bisgard. Independent Marshfield connection.

Mr. Porter. We appreciate and obviously agree with the thrust of your testimony. As I said, we're going to do our very best to be there.

Thank you so much for coming to testify.

Dr. Bisgard. Thank you.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

Wednesday, February 4, 1998.

WITNESS

BETTYE GREEN, NATIONAL BREAST CANCER COALITION

Mr. Porter. To accommodate my colleagues' schedule, I'm going to go out of order and call on Bettye Green, member of the Board of Directors of the National Breast Cancer Coalition and Founder of Women in Touch, an Indiana based breast cancer group, to testify in behalf of the National Breast Cancer Coalition.

To introduce her, our colleague Representative Tim Roemer. Tim, thank you for coming down.

Mr. Roemer. Thank you, Mr. Chairman. Thank you for your time.

I'm going to be brief so you can get to my constituent. I

just want to introduce her to you and to members of Congress hearing this testimony. First of all, before I introduce my constituent Bettye Green, I want to tell you that she's traveled here today with her grandson, sitting to her left, who is Anthony Scott from South Bend, Indiana. He looks better than I do, Mr. Chairman. Today, he's in that dapper suit. Also her cousin Anthony Shern from Washington, D.C., over here to my left and your right, Mr. Chairman.

I know her testimony is going to be of great value to you and members of the committee. Bettye Green is not just a constituent of mine. She is a strong community leader. She has been a valued mentor to me, and I am honored to say she is my friend.

Bettye has taken one of the most devastating events that can happen to a human being and turned it into a crusade that has educated thousands of people around Indiana and around the country. A nurse with over 20 years of experience at St. Joseph Medical Center, she also serves on a number of prominent national boards that deal with breast cancer awareness and education.

There are too many for me to number in the short time that I have here, but I will say that Bettye's talents have caught the eye of Cabinet secretaries and Presidents. She has been nurse of the year, woman of the year, and founder of the program, Women in Touch.

She is a national leader in the fight for better health care for African-American women, and indeed, all women. I would conclude by telling my colleagues on this panel that when Bettye Green has something to say, and she has a lot to say, I know well enough to listen, learn and help. I commend her views to you, Mr. Chairman, and I commend you for all the help that you've been in this crusade to better educate women around the country. You have been a tremendous spokesperson for this cause, Mr. Chairman, and we all thank you.

Mr. Porter. Tim, thank you.

Ms. Green, if I were you, I would take Tim wherever I go, with that kind of introduction.

Ms. Green. I think you should hear the introduction I've given Tim a few times. It's a mutual admiration society.
[Laughter.]

I want to thank you, Mr. Chairman and members of the committee, for all of your previous hard work and leadership and working together with the National Breast Cancer Coalition to create support for the battle to eradicate breast cancer.

I am Bettye Green, a member of the executive board of directors of the National Breast Cancer Coalition. I am the founder of the Women in Touch breast group, which educates African-American women about breast cancer. I'm a wife, a mother, a nurse, and a breast cancer survivor.

I was only 36 years old and still had children living at home when my husband and I discovered I was diagnosed with stage two breast cancer. Most African-American women who are diagnosed with breast cancer at that young stage in their life don't live to tell their story. However, I was lucky.

After receiving chemotherapy and undergoing a mastectomy, I have thus far survived my breast cancer and now I am able to enjoy what so many people are able to take for granted in life,

including my grandson Anthony, who is here with me today. That is why continued appropriate research is so vitally important.

As you know, the NBCC, a grass roots advocacy organization made up of over 400 organizations and hundreds of thousands of individuals, have been working since 1991 toward the eradication of this disease through research and access to quality health care. Breast cancer costs this country untold dollars in medical costs, lost resources, lost productivity and in lost lives. The war against breast cancer, the search for answers to what causes the disease, how we can prevent it, how we can cure it, these are immense issues requiring a concerted, coordinated effort on a national level.

Breast cancer is just not an issue for one month. It is an ongoing crisis. However, we believe we are at a brink, a historical moment for cancer research. The fight against cancer has gained extraordinary momentum at all policy levels. Building on the leadership provided by this committee, the Administration has announced a new cancer initiative.

There is a new energy and optimism in the U.S. in both the scientific and consumer communities about cancer research, a universal feeling that the significant past research investments are poised to pay major dividends in the area of cancer prevention, detection and treatment. We are closer than ever before to reaching our goal of eradicating breast cancer.

Women are depending on Congress to continue to help make that goal a reality. We believe Congress can respond by appropriating \$650 million for peer reviewed breast cancer research for the fiscal year 1999 at NIH, and offering significant support for clinical trial programs, so that research from the laboratories can be translated into treatment for patients.

As we are increasingly optimistic about the future, we must keep in mind the reality that 46,000 women will die of breast cancer this year, and that 180,000 additional women will be diagnosed with the disease. We must acknowledge that each of those women are still receiving the same primitive slash and burn therapies as cancer victims did 25 years ago. This disease is complex, and there is much work to be done.

The research simply needs to continue, so that urgently needed answers to the questions around breast cancer can be found. The women with breast cancer and those who live in fear of this disease deserve information they can depend on, better quality treatment and answers that come one step closer to saving their lives. This can only happen if we have the right research.

Mr. Chairman, you and your committee have been extraordinarily supportive of the needs for increased breast cancer research funding. The NCI is also acutely aware of the need. Breast cancer was cited as a major priority for NCI in their budget proposal for fiscal year 1999. The National Breast Cancer Coalition is calling on Congress to appropriate \$650 million to NIH for peer reviewed breast cancer research for the fiscal year 1999.

If the funding levels for breast cancer research are not increased, the forward progress we have begun to make in these past years will be lost. As cancer research funding is increased, it is critical to ensure that funding for breast

cancer research continues to increase. We believe it is imperative that as increases are made for cancer research in general and NIH and NCI that increases are also made in breast cancer research funding.

The rate of increase for breast cancer research has been declining. Yet each year, the committee states unequivocally that breast cancer research is of the highest priority. This trend needs to be examined and analyzed to ensure that imperative research opportunities are not lost.

We believe strongly that this year the scientific opportunities are such that an investment of \$650 million for breast cancer research can be well spent. As you know, the NBCC is resolute in money not being wasted. Last year, when there was an attempt to divert \$14 million from NCI funds to unneeded funds for the National Action Plan on Breast Cancer, we fought for that money to stay with NCI for peer reviewed research.

We also feel strongly that funds appropriated for breast cancer must be invested strategically. For years, we have not asked for much more money than NCI was spending on breast cancer research, but also that that money was being spent well. NCI has finally heard our demand.

We welcome the progress review group, PRG, which Dr. Klausner has convened through NCI. And you should be hearing a report in 1998.

We want to say in closing that we like the fact that you have heard our word, that you understand what we want, and we do want to follow the President's lead on making sure that money is available for clinical trials. Because as you know, only 2 percent of women participate in clinical trials. If we have the money appropriated which the President has asked for, we're trying to endorse that, we hope that that money will be appropriated for clinical trials and that we do get the \$650 million for breast cancer research.

And thank you so very much.

[The prepared statement of Bettye Green follows:]

[Pages 1733 - 1737--The official Committee record contains additional material here.]

Mr. Porter. Ms. Green, thank you so much. Obviously we're going to take your advice to heart.

Anthony, I want you to do me a favor, and remember as you get older what a tremendous advocate your grandmother was for breast cancer research. And maybe you'll be able to look back and say, I remember when this disease stopped afflicting people on this planet, and she helped cause that to happen.

Tim, thank you for joining us.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

Wednesday, February 4, 1998.

WITNESS

REVEREND GARY HUTCHESON, NATIONAL PSORIASIS FOUNDATION

Mr. Porter. Reverend Gary Hutcheson, Member of the National Psoriasis Foundation and Senior Pastor of the Woodbridge, Virginia, Church of the Nazarene, testifying in behalf of the National Psoriasis Foundation.

Reverend Hutcheson.

Rev. Hutcheson. Good afternoon, Mr. Chairman.

As I have sat these last three hours, I have developed a real appreciation for your skill in this extended exercise of intensive listening. I really appreciate that.

My name is Gary Hutcheson and I'm here this afternoon as an advocate on behalf of the 6.5 million American men, women and children who are battling psoriasis, a chronic, debilitating skin disease. It is a disease without a cure at the present time. And without universally effective treatments.

Until a cure or more effective treatments are found, millions of people with psoriasis face a lifetime fighting this debilitating disease. Over \$3 billion are spent annually on treatments for psoriasis, and each year, psoriasis patients make approximately 2.4 million visits to dermatologists in our country.

Psoriasis is unpredictable and unrelenting. Treatments are often successful for only relatively short periods of time, and then only for some people. The thick, red scaly patches on all parts of the body and painful joint movement limit daily activities and interfere with physical, occupational and psychological functions.

Physically, skin affected by psoriasis itches, burns, stings, cracks and easily bleeds. The occupational impact of the disease poses an economic burden for our Nation, and significant financial hardships for psoriatic patients. Emotionally, psoriasis can be devastating. The social rejection and physical suffering of psoriasis has even led some people to commit suicide.

Some types of psoriasis require hospitalization and can even be diagnosed as life threatening. Each year approximately 400 people with psoriasis are granted complete disability benefits by the Social Security Administration because of the effects of the disease.

Perhaps even more difficult is the fact that three quarters of a million people diagnosed with psoriasis are under the age of 10. Though I certainly do not want to sensationalize my personal situation, I have had psoriasis for the last 20 years. So I can relate something of the pain, embarrassment, and private disgust that the vast majority of psoriasis sufferers struggle with throughout their lives.

On two different occasions, I have been hospitalized for extended periods of time to treat the disease. On numerous occasions, I have received as many as 30 injections directly into the psoriatic patches in a single doctor's office visit.

Early in my career, I was compelled to change my vocational direction from working with troubled teenagers due a pastoral ministry setting due to the rapid advance of the disease. I have even relocated my family at doctors' and clinicians' advice from one part of the country to another in an effort to

find the most advantageous combination of climate, UV radiation from the sun, and specialized medical expertise for treating this tenacious malady.

A task as simple as taking a bath has become a painful, time consuming ordeal. In fact, the derogatory comments and uneasy stares of strangers are not nearly as traumatic for me at this point in my life as the countless hours spent continually soaking in cold tar baths, applying numerous topical steroid treatments, wearing occlusive plastic suits to bed, undergoing regularly scheduled liver biopsies, and receiving weekly ultraviolet light radiation treatment.

The vast majority of psoriasis patients are all too familiar with the devastating emotional roller coaster ride from the trial and failure scenario of current treatment options. Now, I know that my experience is certainly not unique. Through my affiliation with the National Psoriasis Foundation, I have come to understand that my struggle with this disease has not been nearly as devastating as that of hundreds of thousands of other victims.

Like diabetes, arthritis and heart disease, psoriasis requires lifelong treatment. Unlike these diseases, psoriasis is not, or perhaps it would be better stated, has not been in the past, a top priority for research. Yet with recent excellent research conducted by NIH and NIAMS, effective treatment and a cure for psoriasis is within reach.

Sufficient funding in the future will enable medical science to complete the puzzle and find a cure for this affliction. This will not only benefit the 6.5 American children and adults now suffering with this chronic disease, but will also help with the over 200,000 new cases of psoriasis diagnosed each year.

Better treatments or a cure for psoriasis will result in both savings to the public and the government in treatment costs, lost work days and Social Security disability claims.

Finally, on behalf of the 40,000 members of the National Psoriasis Foundation, and the 6.5 million American citizens with psoriasis, I urge you to approve an increase of 15 percent over current funding levels for NIAMS in the fiscal year 1999. This increase will have significant health and socioeconomic benefits for the millions of Americans who are affected by psoriasis and by other diseases under the purview of NIAMS.

Thank you, sir, so much for your attentiveness and your support.

[The prepared statement of Gary Hutcheson follows:]

[Pages 1740 - 1744--The official Committee record contains additional material here.]

Mr. Porter. Reverend Hutcheson, is there any indication about the basis of the disease? Has the research gone far enough to give us an indication? Is it genetically based? Is it environmental? What do we know about that, if anything?

Rev. Hutcheson. Just within the last couple of years, sir, because of research done by NIAMS, several possible sites for genes have been identified that may cause this inherited--it

does seem to have a link to our heritage, this particular condition. But there is no direct known cause for it at the present time.

Mr. Porter. Obviously, the story that you tell is very tough and tragic. Obviously, we want to do what we can to try to get some resources there, and we'll do our best.

Rev. Hutcheson. Thank you, sir. We appreciate it.

Mr. Porter. Thank you for testifying.

Wednesday, February 4, 1998.

WITNESS

BRUCE DAVIDSON, BLUE CROSS BLUE SHIELD ASSOCIATION

Mr. Porter. Bruce Davidson, Senior Vice President, Government Programs, testifying in behalf of the Blue Cross Blue Shield Association.

Mr. Davidson. Mr. Chairman, I am Bruce Davidson, Senior Vice President of Government Programs for Florida Blue Cross and Blue Shield. After listening to the testimony here of a number of these very distressing diseases and conditions, I am not here to talk about that, I'm here to talk about the funding for the contractors who pay, hopefully compassionately, wisely for the Medicare beneficiaries who are afflicted by many of these conditions.

I'm testifying on behalf of the Blue Cross Blue Shield Association, which represents 55 Blue Cross and Blue Shield member plans throughout the Nation. We certainly appreciate the opportunity to testify on the fiscal year 1999 budget for Medicare contractors.

We come before you this year with an urgent message, Medicare contractor funding must be increased significantly in 1999 to meet all of the new demands facing the contractors, but especially to help them combat Medicare fraud and abuse effectively. Our written testimony covers several areas, but this afternoon, I'd like to focus on the role of claims payment. We in HCFA call it program management in anti-fraud and abuse efforts.

Both the Congress and the Administration are exploring ways to strengthen the efforts to detect and prevent Medicare fraud and abuse. I know this is a high priority of your subcommittee. We agree that more can and should be done.

However, this priority cannot be addressed and the benefits of the increased Medicare integrity program funding cannot be maximized without an adequately funded program management or claims payment function. Many think of program management as simply paying claims. While the separately funded Medicare integrity, or we call it MIP function, is entirely dedicated to the detection of fraud and unnecessary payments, the first line of defense is the program management function of the contractor. It also has very significant responsibility for mopping up, if you will, after the MIP activities, as I will describe.

Let me describe the basic relationships between program management and Medicare integrity activities. First, based on input from HCFA, the contractor's MIP function and other

experience, a contractor's program management function puts into effect front end edits which stop a claim from automatic payment. In Florida's Part B system, there are hundreds of such edits. Many of the edits are used nationally, but most are a result of local conditions.

This stoppage of automatic payment results in a denial or a review by a claim examiner and then a decision of payment or non-payment. More aggressive edits result in more no-payment decisions, which increase reviews, inquiries and hearings, all of which are program management functions.

Additionally, many of the edits require that supporting documentation be mailed to the contractor, and this reduces the automatic payment rate, which has been a prime source of contractors' ability to process more claims with less funding.

Second, a contractor's MIP function will identify providers and services which are suspect to fraud and abuse, and review all or a sample of claims coming from those providers or from those services. This results in claims denials, which then create more inquiries, reviews and appeals, again, functions of program management.

Lastly, post-payment reviews by the MIP function result in increased over-payment recovery activities which are the responsibility of the program management function.

In 1994, Florida subjected about 4 percent of our Part B claims to pre-payment review. Today we're up to 8 percent. We estimate that each increase of 1 percent raises program management costs by at least \$1.4 million. The fact that Florida's program management funding is inadequate, and our MIP function is very active, is indicated by our rising review and appeals backlog. And we're just not keeping up with it.

In Florida, we have the program management and MIP functions split and assigned to two separate managers. I can tell you that the MIP manager has a number of edits, suspect providers and services that he would like to subject to increased scrutiny. However, the program manager does not have enough resources to cope with the volume of work that was a result.

This means that we are bypassing the opportunity to save Medicare funds because the program management function is not funded to match the ingenuity and activity level of the MIP function.

Additional program management funds are needed to handle the additional work load generated by the enhanced anti-fraud and abuse initiatives. Medicare savings cannot be realized unless all segments of contractor operations are adequately funding.

In closing, I would like to underscore that Blue Cross and Blue Shield Medicare contractors are proud of their role as Medicare administrators. In 1998, contractors' administrative costs represented less than 1 percent of total Medicare benefits. That's a statistic we can be proud of on the one hand, but be worried about on the other. Because we know that with more funding, we could achieve much greater program savings by reducing fraud and abuse.

Given the importance of Medicare to its beneficiaries, providers and the Nation's economy, it's critical that the administrative resources necessary to effectively manage the

program be provided.

Thank you very much.

[The prepared statement of Bruce Davidson follows:]

[Pages 1748 - 1758--The official Committee record contains additional material here.]

Mr. Porter. Mr. Davidson, the bottom line on the president's budget indicates they're suggesting a small cut in Medicare contractors. We understand that they're proposing some new spending for contractors that is unauthorized, and it's funded with user fees. Can you fill me in on that? We don't have jurisdiction, obviously, over user fees.

Mr. Davidson. Right. I was briefed on that just this morning. And it was a brief brief.

My understanding is that the user fees will have to be enacted legislatively. Basically they are a tax on providers for paying for the costs of being audited, paying for the cost of submitting paper claims.

My knowledge of both of those activities and the providers that would be engaged in that legislation would be that it's going to be some tough sledding to get that legislation passed.

Mr. Porter. I will have to try to figure that out, obviously, and ask the committee of jurisdiction. I suspect that this appropriation will kind of remain up in the air until we get to conference and see what has or what might occur.

But I think you're probably right, my guess is that all of the revenue portions of the President's budget probably are unlikely to be adopted, although I certainly would stand to be corrected on that. My own feeling is, it's unlikely they are going to be responsive to those, and that will leave us kind of in limbo for a while.

Thank you for your testimony. We very much appreciate it.

Wednesday, February 4, 1998.

WITNESS

CAROLINE MYERS, NATIONAL FUEL FUNDS NETWORK

Mr. Porter. Last but not least, Caroline Myers, Chair of the National Fuel Funds Network Board of Directors and Executive Director of Crisis Assistance Ministry in Charlotte, North Carolina, testifying in behalf of the National Fuel Funds Network.

Thank you for your patience, Ms. Myers.

Ms. Myers. Thank you, Chairman Porter, for allowing me this opportunity to be here. I'm pleased to represent the National Fuel Funds Network as its chairperson. We support LIHEAP funding, the Low Income Home Energy Assistance Program, at no less than \$1.3 billion for fiscal year 1999. We are also pleased about the fact that there is forward funding to be approved for 2000. We would like to propose that that level of appropriation be increased to a \$1.5 billion figure.

The National Fuel Funds Network is a membership

organization comprised of over 200 dues paying representatives of private fuel and energy assistance funds, community action agencies, social service organizations, utility companies, trade associations and private citizens. Our member organizations are located in 44 States and the District of Columbia. We're concerned with the ongoing energy crisis that exists for the poor in America.

As I've listened to these very moving testimonies that you've heard today, I think there is another disease in your country called poverty that is very much with us, and to which all of these people might be subject as well. I want to tell you a little bit about the Crisis Assistance Ministry where I have worked in Charlotte since its founding in 1975.

We provide emergency energy assistance, and several other basic needs as well, in an effort really to prevent homelessness among our community's low income citizens. Every day at this time of year, more than 100 people come to our door. There are others on the phone hoping to get a chance to get in and to have their needs met. About half of those are heat related kinds of needs.

We've been administering emergency LIHEAP funds since 1982 for Mecklenburg County. We also administer the local fuel funds of Duke Power Company and Piedmont Natural Gas, as well as our own fuel funds that we raise from the religious community and individuals.

Ours is an unusually generous, caring and prosperous community. We're fortunate indeed to have all those resources in place.

However, the fact is that the need we're seeing even in this prosperous community is increasing by about 20 percent. We're still not meeting all the need. That is the bottom line. We cannot begin to do so without the basic resource of a LIHEAP program with increased funding. That has been core to the work that we've been doing, but the need is still greater than that we're able to meet.

All the fuel funds get involved in this business of trying to find other ways to meet these needs. The families that LIHEAP serves and that the fuel funds serve have incomes of less than \$10,000 annually. The fuel funds themselves make heating and cooling assistance payments only of about \$72 million a year. I say only, knowing how hard that is to raise.

We do that on behalf of about 500,000 families. And that's very important money. But it can't begin to approach the importance of a \$1.1 billion program that is now in place for fiscal year 1999 in LIHEAP funding.

Fuel funds are unable to fill the gap between the need for assistance and the available fuel funds. People continue to heat with unsafe methods, and I think that you all are aware of that. Most of us don't know what it's like to live without power. That's what many families really do have to do in places where there are no local fuel funds. We read tragic stories about the results of that.

This is one case in point, flipped heater causes fatal fire, out of a recent paper, Charlotte Observer.

As the director of a crisis program, I'm often asked, what kinds of folks are these that you're seeing. And here's a profile of what they look like. Seventy-one percent of the

clients that we see are below Federal poverty guidelines, at least in the 30 days before they came to our operation.

They pay as much as 21 percent of their already income to heat and light their homes. They have discretionary income problems. For them, that means they're trying to make decisions about whether to have enough food or whether to have heat, or whether to buy medicine. Their dilemma, regrettably, is which necessities do we do without.

Almost 70 percent of the people that we help do have earned income, however, a very important fact, I think, to be aware of. They do lack reserves and perhaps benefits on their jobs. But they for the most part are working, working very hard with often heroic efforts to maintain two jobs, so that when the hours are cut back on the other job, they'll be able to make it.

Other recipients are disabled and struggling to pay monthly expenses in winters when gas or fuel prices might rise by 30 percent or so.

I not only represent NFNN here today and Crisis Assistance Ministry, but I also feel like I represent the people that we serve. Because I've been working with them so long. One of the things that our clients do for us is, they write notes as they leave. I just wanted to read a couple of those messages from those people. I have books of these kinds of testimony, actually.

I just wanted to thank the people who helped me in the past, so my children could have power. Signed by Tony. It was cold inside and my house felt like ice. But thanks to a very special person who cared, Crisis Assistance Ministry was able to have my gas restored. Thank you, may God bless you.

I want to thank Crisis Assistance Ministry for helping me. Your assistance helped me get my gas back on. Dear sir or madam, thank you for all of your help. In my case, I really do thank you. Now my two year old son will be able to stay warm.

These are the very stories that are out there. There are many of them that I could share more with you. But that's what I have witnessed over the years.

We're making generalizations, I know, about the poor. But there are just many circumstances that can happen in peoples' lives that make it so that for a time being, at least, people face this kind of an emergency.

LIHEAP has just not kept pace with the increased number of poor and with the erosion of the income that the poor are receiving. The thing that we are really looking at in the years ahead is the impact of welfare reform.

Now that we are doing some very significant things to create really perhaps more working poor, they are going to need the kind of support system that must be there so they don't fall off the edge, so that they can indeed meet the basic needs of their families and keep them warm and able to function. Alarm clocks don't go off, either, without electricity. So LIHEAP must play this increasing role in welfare reform transition.

Former public assistance recipients for the most part will make these low wages. In Charlotte, a living wage has been determined to be at about \$13 an hour. So you see, there is quite a gap that's got to be filled somewhere.

[The prepared statement of Caroline Myers follows:]

[Pages 1762 - 1766--The official Committee record contains additional material here.]

Mr. Porter. Ms. Myers, is your request the same as the President's budget?

Ms. Myers. The President's budget, I believe is 1.14.

Mr. Porter. I think it's 1.3.

Ms. Myers. Is it?

Mr. Porter. I thought it was.

Ms. Myers. We have some other folks, Pat Markey may know the answer to that better than I.

Mr. Porter. It's 1.4, then, is that correct?

Ms. Markey. It's \$1.1 million in core funds, plus an additional \$300,000.

Mr. Porter. I thought that your request was 1.3, so it's 1.3 as opposed to 1.1.

Ms. Myers. Right.

Mr. Porter. So you're asking for more than what the President's asking for?

Ms. Myers. Exactly. And in the forward funding for 2000, a larger increase.

Mr. Porter. Right. Well, let me say that obviously the need is very great. My colleague over on the Senate side, Senator Specter, has been a very great champion of LIHEAP funding. I think you can probably be pretty well assured that he's going to be a champion again this year.

Ms. Myers. I certainly hope so.

Mr. Porter. We have not been nearly as strong. But when it comes out in the conference, the Senator has consistently been there, and been a very strong supporter of LIHEAP. And it undoubtedly will end up the same way.

Ms. Myers. Good.

Mr. Porter. That's good news.

Ms. Myers. Thank you.

Mr. Porter. I personally have some problems with the rationale of the program, which I don't think we can debate here at this point in time, but I think you're exactly right, that the need is very great, the population served must have this assistance. And I have been urging the authorizers to look at the concepts of the program in a different way for the reasons that I believe the rationale has ceased to exist. But absolutely, there's no question about the need and the funds have to be provided in some way.

Ms. Myers. And the graying of America certainly impacts this program, too.

Mr. Porter. And you mentioned welfare reform, and of course, that's right, also.

Ms. Myers. Right.

Mr. Porter. So thank you very much for coming to testify. We're sorry you had to wait so long. But it's been a day filled with a lot of votes that we simply can't anticipate.

Ms. Myers. Thank you for your attention.

Mr. Porter. Thank you so much.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

The subcommittee will stand in recess until 10:00 a.m. tomorrow.

Thursday, February 5, 1998.

WITNESS

BENJAMIN PAYTON, TUSKEGEE UNIVERSITY

Mr. Porter. The subcommittee will come to order.

This is the final panel of our public witnesses. We have heard roughly 160 witnesses to this point, and I want to thank all of you for coming to testify.

I have up to this point been asking a fair amount of questions. Today I am not going to be able to do that to any extent because I have a speech off the Hill between the morning panel and the afternoon hearings, and we are going to have to complete our panel by the appointed time.

I thank you all for coming. We have allotted 5 minutes to each witness. Our staff has a new innovation, as you may have heard, a timer that will indicate the end of the 5-minute period, and we would ask that you complete your thought and then complete your statement as promptly as possible.

Our first witness is Benjamin Payton, president of Tuskegee University, representing the university. Dr. Payton, it is nice to see you, sir.

Dr. Payton. Thank you, sir. Good morning, Mr. Chairman, and thank you, members of the committee, Congressman Stokes and others.

I want to first express my appreciation to you, Mr. Chairman, for the extraordinary leadership that you have provided this committee, and I hope you will permit me to say a word of special thanks to Congressman Stokes. He has recently announced that he is going to be retiring from the Congress this year, and many of us feel a deep pain at that, Congressman. You have been such an outstanding presence on this Hill.

As a matter of fact, I want to, if you will permit, Mr. Chairman, to begin my few remarks by reading a quote from a recent article Congressman Stokes wrote in an issue of the July Roll Call. He says this, and I quote:

In recent years, we have seen unprecedented advances in biomedical research, the diagnosis of disease, and the delivery of health care services. However, African Americans, Hispanic Americans, Native Americans, and those of Asian/Pacific Islander heritage have neither fully nor equally benefited from these new discoveries. Rather, minority Americans continue to face historical barriers to good health, such as poverty, poor nutrition, and lack of access to quality health care, which has severely compromised their health status.

That, Mr. Chairman, is an excellent summary of the biomedical challenges that we face in our society, as so eloquently stated by Congressman Stokes.

I wanted to add to that a new dimension of the whole health field that now confronts our society and the entire modern world and the entire world, and that is what has come to be known as the challenge of bioethics.

It is now critical that all Americans understand, and particularly the health and medical communities, those who are not only the deliverers of health care but those who teach it, as well as the American society, that science and medicine are not autonomous enterprises. These are activities that have to function in the context of moral and social values which are the texture in which we develop as a people.

One of the great challenges that we face now is that we have developed a new discipline over the past 15 or 20 years that is called bioethics, and it means really what it says: bios ethic is the ethics of life, it is about bringing the disciplines of philosophy and ethics and the humanities to bear on the activities which comprise the health and medical care establishment.

Bioethics is important, Mr. Chairman, because we have made some grievous errors in this society, particularly with respect to African Americans and people of little power. Those grievous mistakes have been symbolized, have come to be symbolized in an experiment that is popularly known as the Tuskegee experiment.

I am Benjamin Payton. I am president of Tuskegee University. For more than 40 years, the United States Public Health Service hid behind the name Tuskegee while it, the United States Public Health Service--not Tuskegee--conducted an experiment on poor, defenseless black males, illiterate people who didn't know really what was going on. And that experiment was designed to just see what would happen when syphilis is untreated and left to make its own course. Even when penicillin and effective treatment became available, that treatment was denied these persons who were participants in this experiment.

This so-called Tuskegee experiment has come to represent the height of infamy in the conduct of health and medical research in our society. But it has done something else, Mr. Chairman. It has created a tremendous undertow of suspicion and cynicism among African Americans and many people without power in this society and, thus, an unwillingness to participate in the kind of trial clinics which are so important if we are to continue the process of discovering new cures for disease.

It is important, if those cures are to be developed, that all Americans participate in these trials. So our great challenge is how do we overcome this heritage of suspicion, rightly rooted, in part, in the abuses of the system, but also now forwarded by the absence of significant participation of minorities in the bioethics disciplines which make it possible for us to understand the new developments that are occurring as a result of the impact of science and technology in our society.

To just illustrate quickly that impact, there are articles now appearing all over. There is one scientist, for example, who wants to clone a human being and says he is going to do it in spite of the fact that the President's National Commission on Bioethics has recommended that all cloning of human beings cease and not occur.

There are incidences which have occurred right here in

Washington, D.C., where people from poor families have had their deceased relatives in hospitals; the organs have been removed, it has been reported, before death in order that those who can use them and can pay for them can have access to them.

We have people who are interested in really doing--a few, fortunately not too many, we don't think--what was begun by the Nazis in Germany, and that is, to create a science of genetics to develop a superhuman race.

Mr. Chairman, these kinds of issues are the kinds of issues that all Americans must become knowledgeable about and trained about. Minorities, African Americans and others, particularly, have got to understand the protocols governing research so that they can respond in intelligent ways to these challenges. Thus, they request for this committee for an appropriation to follow the \$4,000,000 you authorized last year and we have received to create the first bioethics center in health care and research on a historically black college campus, at Tuskegee University.

We are most grateful for that, Mr. Chairman, and to this Congress. This was announced by President Clinton. It has the support of the executive branch. It is a bipartisan effort. In order to bring it to completion, we will need appropriations this year in the amount of \$18,000,000 which we are coming forward to ask this committee to give its serious consideration to.

This will be a path-breaking program that would enable us to make tremendous progress as a total society, Mr. Chairman.

[The prepared statement of Benjamin Payton follows:]

[Pages 1772 - 1779--The official Committee record contains additional material here.]

Mr. Porter. Dr. Payton, thank you very much for your testimony. Obviously we cannot change the past, and I don't know the facts of the study you mentioned, but we can change the future. We will take your thoughts and your testimony into account in our deliberations, and let me say I can't agree more that--and I told Mr. Stokes this yesterday. He is virtually irreplaceable, and I don't know what we are going to do without him. But we are going to take advantage of his last year in the Congress, and he will continue to be the strong advocate that he has always been.

Dr. Payton. Thank you.

Mr. Porter. Thank you, Dr. Payton.

Mr. Stokes. Thank you, Mr. Chairman. If I may?

Mr. Porter. Mr. Stokes?

Mr. Stokes. I certainly want to respect the time aspects of this morning's hearing. I just want to thank Dr. Payton for the eloquent statement he has made here this morning. Mr. Chairman, I want to thank you and the other members of the subcommittee for the manner in which you responded to the President's request and Dr. Payton's request relative to this appropriation by appropriating \$4,000,000 in the fiscal year 1998 bill.

Certainly, I hope that we will be able to comply with your full request, Dr. Payton, but I certainly appreciate the manner in which you have responded, Mr. Chairman, as well as the other

members of this subcommittee.

Mr. Porter. Thank you, Mr. Stokes.

Thank you, Dr. Payton.

Mr. Payton. Thank you very much, Mr. Chairman.

Thursday, February 5, 1998.

WITNESS

RICHARD O. BUTCHER, SUMMIT HEALTH COALITION

Mr. Porter. Our next witness is Richard O. Butcher, M.D., President, Summit Health Coalition, testifying in behalf of the coalition.

Dr. Butcher.

Dr. Butcher. Good morning, Mr. Chairman and distinguished members of the subcommittee. Thank you for this opportunity to speak with you this morning on behalf of the Summit Health Coalition. I am Dr. Richard Butcher, a family practitioner in San Diego, California, for the past 30 years. I have served as president of Summit Health Coalition since its inception.

Summit Health Coalition is a network of 50 national, State, and community-based organizations, primarily African American. Since 1993, our focus has been to advocated for health care policies that will meet the needs of underserved populations.

This subcommittee has supported programs of critical importance to the members of our coalition, and we appreciate your leadership in this regard, Mr. Chairman.

We also join Dr. Payton in recognizing the extraordinary accomplishment of Congressman Louis Stokes. We can think of few Members of Congress, past and present, who have made such a lasting contribution. Congressman Stokes, the Summit Health Coalition salutes and we thank you.

Today's headlines announce this as a time of uncommonprosperity in America. Unemployment is down, tax revenues are up, and there are even projections of a budget surplus. Yet in today's booming market economy, some people are still not benefiting. Many of them are our constituents.

At the same time, the passing of the Balanced Budget Act in the last session of Congress is bringing about a transformation in the way health care is provided in our communities. Many of these changes are positive. But a substantial number of our constituents are experiencing challenges and disruptions that we believe were not intended by Congress. We would like to recommend some proposals this morning that will address these unintended consequences.

Our recommendations deal with four areas.

First, our first recommendation is that Congress provide the funds necessary to strengthen HCFA's capacity to protect Medicaid and Medicare beneficiaries enrolled in managed care. We know that the workload of the Health Care Financing Administration has increased dramatically as a result of new laws enacted in 1996 and 1997. At the same time, HCFA must take steps to ensure that beneficiaries are helped, not harmed, as health delivery systems change. These are the reasons we support increased funding for HCFA oversight monitoring and collection of data on managed care procedures and outcomes by

race and ethnicity.

We also urge increased funding for the consumer education with respect to managed care. We specifically recommend that the HCFA budget for research, demonstration, and evaluation be increased by \$25,000,000 over last year's level. This increase is necessary if HCFA is to respond meaningfully to Congress' request made last year. You asked that HCFA demonstrate and evaluate community-based model programs to help vulnerable populations understand how to use managed care. This is a very important need. HCFA also needs to conduct research on the impact of managed care on consumers and providers, particularly in minority and other underserved communities.

We also urge consideration by Congress of expanded support for insurance counseling assistance programs. Many programs have seen counseling requests increase dramatically with the coming of managed care while funding has been the same for the last 3 years.

With regard to the Health Resources and Services Administration, we strongly urge this subcommittee to continue its leadership role in providing support for historically black health professional schools and scholarship programs for minority students.

We are very concerned that access to health care in minority communities will be severely limited if there isn't a concerted effort now to maintain and expand the number of African American health professionals and institutions. This is why we wholeheartedly endorse the Disadvantaged Minority Health Professions Amendments Act of 1997.

We also urge budget increases for community health centers and other essential community providers who provide health care to the uninsured.

With respect to other department initiatives, we strongly support the adequate funding for the Office of Minority Health and the Office of Research on Minority Health at NIH. We enthusiastically endorse the President's initiative on race. We believe, in addition, that there must be adequate funding for inclusion of African Americans and other vulnerable populations in clinical trials.

Summit will be sharing detailed legislative proposals on tobacco control with you in the days and weeks to come.

Mr. Chairman and members of the subcommittee, we invite you to review our written statement for additional information on these recommendations. Thank you for this opportunity to bring the concerns and proposals of Summit Health Coalition to your attention.

[The prepared statement of Richard Butcher follows:]

[Pages 1783 - 1790--The official Committee record contains additional material here.]

Mr. Porter. Thank you, Dr. Butcher. That was perfect. It couldn't have been better. We will very definitely read your written submission and take your views into account when we mark up the bill.

Thank you for coming to testify.

Dr. Butcher. Thank you, Mr. Chairman.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

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WITNESS

MERRILL MATTHEWS, JR., PH.D., NATIONAL CENTER FOR POLICY ANALYSIS

Mr. Porter. Dr. Merrill Matthews, Jr., Vice President, Domestic Policy, National Center for Policy Analysis, testifying in behalf of the Center.

Dr. Matthews?

Dr. Matthews. Good morning, Mr. Chairman and committee members. I would like to take this opportunity to thank the committee for this opportunity to testify before the committee. My name is Merrill Matthews. I am a Ph.D. I am Vice President of Domestic Policy for the National Center for Policy Analysis, a nonpartisan, nonprofit research institute based in Dallas.

In 1995, the Department of Health and Human Services, including the Social Security Administration, spent \$665,000,000,000, according to the Department's own published figures. That amount represented 44 percent of the Federal budget that year.

One of the largest agencies under HHS, the Health Care Financing Administration, HCFA, had a total budget of \$269,000,000,000 in 1995, or 16.4 percent of the Federal budget.

I am going to take a little bit different track than my two predecessors, and I am going to talk just a little bit about how to downsize Government rather than add more. Clearly, Mr. Chairman, if Congress is going to look at downsizing Government, if it is serious about it, we are going to have to look at the Department of Health and Human Services.

Unfortunately, trends created by both Congress and HCFA itself have been moving in the opposite direction. As was mentioned just a minute ago, Congress had passed legislation in 1996 and 1997 which expands HCFA's oversight and is going to give them more responsibilities, and they don't have enough people probably to handle that.

In addition, Congress is looking at future things. The President has suggested several things in his new budget which would increase the oversight and size of the Health Care Financing Administration. Congress is also looking at various types of consumer protection laws which could create a new huge burden on HCFA to oversee the hundreds of managed care companies that are out there in the country. That would represent a huge growth in HCFA.

In addition, HCFA itself has not been without some responsibility here. They have been seeking to grow internally. Even though the new Administrator at HCFA has recently expressed the concern they have about the growth that they are having to experience, the new responsibility, and the lack of funds, in some cases they have actually sought to grow

themselves.

In the budget agreement of 1997, one of the things that they wanted to do in the Medicare Plus Choice program is to become marketers for all the health plans and health insurers out there. As you know, the Medicare Plus Choice program gives people more opportunities, seniors more opportunities to choose between HMOs, PPOs, point-of-service plans, Medicare medical savings accounts, traditional fee-for-service.

In the agreement, HCFA arranged to get \$200,000,000 set aside a year to market these plans to seniors. Now, we find that somewhat strange. Why would the Health Care Financing Administration want to try to become a marketer for health insurance? Imagine an elderly couple, 70-year-old man, 65-year-old woman, both going on Medicare. The man has had a history of heart problems and other medical conditions. The woman, his wife, may have been very healthy, and they decided, What do we want? So they are going to call a representative of HCFA to find out what of these plans they think would be the best ones available for them.

In this budget, which eventually was negotiated down to \$95,000,000, HCFA decided that they wanted to have published brochures, they wanted to have health fairs, they wanted to have a hotline because they were anticipating 6 million calls a year from seniors trying to figure out what they should get in health insurance.

It would be bizarre to imagine that people who have never been trained in health insurance could sit and answer the questions of seniors, many of whom have very difficult problems, trying to guide them on what kind of health plan they could go in.

That is an unreasonable approach for HCFA to take, but they have wanted to do that, and we suggest that that is not a very effective use of their time.

So not only is Congress imposing new oversight on HCFA and they are trying to grow themselves, you are creating a problem within the Health Care Financing Administration which should be curtailed. So I would encourage you in future legislation to consider some of these problems that they are facing.

In addition, let me take a few minutes just to talk about some of the other things that the Department of Health and Human Services has oversight on that could be changed in order to be able to downsize that whole process. One is Medicare. We would suggest that Congress look at the possibility of Medicare privatization, that is, giving people the ability to put their own money in their own account during their working lives so that when they retire, they can use that money to buy health care after retirement, rather than having the huge Medicare bureaucracy oversee this whole process.

In 1995, Congress looked at block granting Medicaid to the States. That budget was curtailed. It was vetoed by the President. We think that it would be a very good time to look again at block granting Medicaid to the States in order to get the Federal Government out of the Medicaid business.

With that, I think my time is up now, so I will stop there.

[The prepared statement of Merrill Matthews, Jr., follows:]

Mr. Porter. Dr. Matthews, thank you for your testimony. Obviously much of what you say we have been attempting to respond to.

When you talk about the size of the overall budget for HHS and for HCFA, you are mainly talking about entitlements or mandatory spending over which this subcommittee doesn't have control. You also have pointed out some things over which we do have control, and I think the points are well taken.

The intention, of course, is to give more discretion to the States. We have done that, not the way we wanted to because the President vetoed it, but we have done it by granting a very, very strong waiver on Medicaid, and many States are proceeding as they basically wish in that area. I think that has been a positive development.

We also have restrained the rate of increase in the entitlement programs, not this subcommittee but the Congress, which I think has been very necessary.

Providing to Medicare-eligible seniors a lot of lesser-cost alternatives--or at least the hope is that they will be lesser-cost--I think has been a very, very positive development in the program. I don't think it--I think I will disagree on one point. I don't think it is a bad thing at all for HCFA to be in the market of helping seniors determine which is the best alternative. One thing we want to do is to move people out of a traditional, very expensive program, into less expensive alternatives. If that is the thrust of what we are doing, I think that is very, very positive.

I also think you need a certain amount of ombudsman services to seniors who won't understand all of these very complex choices, and I doubt that that is something that can be done credibly as well in the private sector, but I could be wrong about that.

In any case, we do aim to make our spending at the Federal level less, to bring more to the States, to make efficient the programs, and the spending that is done at the Federal level in such a way that we are saving resources. We have been doing the best we can to accomplish those goals.

So thank you for testifying today. We very much appreciate it, Dr. Matthews, and we will continue along those lines.

Dr. Matthews. Thank you, Mr. Chairman.

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WITNESS

SUSAN C. SCRIMSHAW, PH.D., ASSOCIATION OF SCHOOLS OF PUBLIC HEALTH

Mr. Porter. Susan C. Scrimshaw, Ph.D., Dean, School of Public Health, University of Illinois at Chicago, testifying in behalf of the Association of Schools of Public Health.

Dr. Scrimshaw, welcome. Nice to see you again.

Dr. Scrimshaw. It is good to see you again, Mr. Chairman. Senor Bonilla, mucho gusto.

I am Susan Scrimshaw, Dean, School of Public Health, University of Illinois at Chicago, and Chair of the Legislative Committee of the Association of Schools of Public Health. And I would like to thank you for the opportunity to present our statement today.

With your permission, I am going to submit the written text and highlight some of my comments, and the written text includes a chart with our recommendations.

First, health professions education. We strongly recommend that Congress tackle a problem that has been left to fester for over a decade: lack of adequately trained health professionals. You will recall that in 1988 the Institute of Medicine found the U.S. public health infrastructure was in disarray and identified serious shortages of public health professionals. This is even more important 10 years later in the era of managed care where still 80 percent of the 500,000 public health workforce do not have graduate education in public health.

There are only about 4,000 certified preventive medicine physicians in the U.S. The estimated need, however, is around 10,000.

My school conducted a study recently and found that only about 25 percent of local public health departments had the staff to adequately address core areas of public health. So, Mr. Chairman, we need your help in seeking solutions to these inadequacies.

We spend over \$6,000,000,000 a year to ensure that physicians are well trained in the medical sciences to treat and cure diseases, and we spend pittance to train professionals to prevent those diseases. This doesn't make sense. As you are well aware, a dollar spent on measles vaccine saves \$12 later. Prenatal care saves us \$10,000 for every premature birth averted. HIV averted saves us \$75,000 later on in costs. So we respectfully request that Congress appropriate at least \$50,000,000 to support HRSA's public health training programs.

In the second area of prevention research, as you are aware, we have 14 prevention research centers that were authorized by Congress, and they are located mostly in schools of public health. They bridge the gap between public health science, research, and academia and public health practice in communities. Our own prevention center at the University of Illinois at Chicago is one of the strongest in the country. To give you an example of the kind of work we do, we have a project that works with grade school children to address prevention of violence, drug abuse, premature sexual activity, smoking, and alcohol abuse, and promotes self-esteem, educational attainment, and a healthy lifestyle.

This program has been so successful it is being adopted for all of the Cook County schools, and other school systems around the U.S. are looking at it as an example.

We have another project in Lake County, Illinois, you may be familiar with, and that is successful in promoting breast and cervical cancer screening. Mr. Chairman, you presented an award at the National Center for Nursing Research to our Dr. Michelle Kelley for her transitions to parenthood project.

We also go on record in support of the administration's

fiscal year 1999 request to fund CDC's extramural research program, but at \$100,000,000 instead of \$25,000,000. That is how strongly we believe in prevention.

Given the importance of prevention, we respectfully recommend that NIH be urged to focus more attention on population-based research strategies, and particularly on behavioral aspects of research. As an anthropologist, I have spent 25 years trying to be a bridge between the health care system and behavioral determinants of illness and the development of strategies to prevent illness and promote healing. We would like to say that we want to promote wellness instead of sickness in this country.

ASPH strongly applauds your efforts to double the NIH budget, and we commend your vision and leadership. We also urge that equal commitment be given to the NIH partners: HRSA, CDC, AHCPR, and OPHS. It is important to improve the health of the American people. Research at NIH is biomedical research, but we need to do the applied and the community-based research to go along with the biomedical.

To give you two quick examples of how important this can be in our own communities, NIOSH funds the ERCs, the education and research centers, and our Dr. Daniel Rahorshek heads the ERC at University of Illinois at Chicago.

Our ERC at UIC has NIOSH funding, and last year we were asked by the city of Lakeforest to do an assessment of bio-aerosols emitted by a composting facility. The assessment was heavily subsidized by our NIOSH funding. We could not have done it without it.

We also worked on methyl parathion, which was illegally applied to hundreds of homes in the greater Chicago area. Dr. Rahorshek chaired the CDC expert panel on methyl parathion. Again, without NIOSH support, we couldn't be doing this work.

Mr. Chairman, I would like to end my testimony by once again commending you and thanking you and the members of your subcommittee for supporting public health service programs in general, and I would like to remind us that public health represents 25 of the 30 years of life expectancy we have gained in America this century, and also commend the President for increasing the AHCPR budget, but note our disappointment at the lack of support for the MCH block grant. We have such a block grant in our State, and I think we are a good example of how important it is to protect mothers and children with this funding.

As I say, you have a written copy of my testimony. I want to thank you very much for your attention and for your hard work to promote a healthy America.

[The prepared statement of Susan Scrimshaw follows:]

[Pages 1805 - 1814--The official Committee record contains additional material here.]

Mr. Porter. Dr. Scrimshaw, thank you for your excellent testimony. We will try to do better than the President did in some of those areas, and I think you have put your finger obviously on something that is very important, that is, moving

from the research to the application of that research to our lifestyles and our health. And we will do our best in those areas, too.

Dr. Scrimshaw. Thank you very much.

Mr. Porter. Thank you so much for coming to testify.

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WITNESSES

JOSEPH GIAMMALVO, PARENT

MICHAEL GIAMMALVO, PATIENT (SON)

GINA CIOFFI, COOLEY'S ANEMIA FOUNDATION

Mr. Porter. Joe Giammalvo, a parent, accompanied by his son, Michael, to testify in behalf of the Cooley's Anemia Foundation.

Mr. Giammalvo?

Mr. Giammalvo. Good morning, Mr. Chairman. My name is Joseph Giammalvo. With me today is my 6-year-old son, Michael. I am also accompanied by Gina Cioffi, the national executive director of the Cooley's Anemia Foundation. I am very grateful to have an opportunity to thank you for your past assistance for Cooley's anemia patients like Michael and to tell you about how much more remains to be done.

At the outset, let me state that because of the work of this subcommittee and the National Institutes of Health, Michael has a considerably lengthened life expectancy. Cooley's anemia patients today often live into their 30s, whereas just 20 years ago, average life expectancy was mid-teens. A brief description of what Michael's life is like will indicate how much more there is to do.

Cooley's anemia is a genetic blood disease that results in inadequate production of hemoglobin, the red oxygen-carrying substance in blood. This causes severe anemia which requires frequent and lifelong blood transfusions to sustain life. Because there is no natural way for the body to eliminate iron, the iron in the transfused red blood cells builds up and becomes toxic to tissues and organ systems, particularly the liver and the heart.

The excess iron must be removed, or the patient will die. This is done by infusion of a drug that is administered for 10 to 12 hours a day by pumping it through a needle inserted below the skin or in a vein.

Michael is my hero. He is the bravest little boy I know. Every day he fights to continue to live. It is a struggle, Mr. Chairman, and many Cooley's anemia patients do not make it. Particularly as they move into their teen years, children tend to become less compliant. Compliance hurts. Compliance means you can't go spend the night at a friend's house. Compliance means you can't be just another kid.

In my written statement that is submitted for inclusion in the record, I go into more detail on the research opportunities that exist to improve the lives of young people like Michael struggling with terrible affliction. But I would like to touch on a couple of those opportunities here.

Last year, a Special Emphasis Panel was convened by NIH to

discuss new therapies for Cooley's anemia. The number one recommendation of that panel was the creation of a network of collaborative clinical centers to study the effectiveness of new clinical interventions for Cooley's patients. This approach has great merit as it would allow for pooling of patients, the creation of common protocols, it would save money and expedite research. It must have been a good idea, Mr. Chairman, because this subcommittee and your Senate counterpart endorsed it in the conference committee report for fiscal year 1998.

Unfortunately, it has not been done.

As a taxpayer, Mr. Chairman, I am greatly concerned when tens of thousands of tax dollars are spent to bring in experts from all over the country to advise the NIH, and their top priority recommendation, endorsed by Congress, is not acted upon. But as the parent of Michael Giammalvo, I am outraged.

Since the report was issued, new research identified many sickle cell anemia patients who have required the same painful treatment as Cooley's anemia patients, greatly enlarging the population that would be served by such a network. And the network is all the more important because significant research opportunities exist.

According to the Special Emphasis Panel's report and according to the independent experts in the field, a couple of examples: Opportunities exist to develop an oral drug to remove iron so patients like Michael won't have to be hooked up to a pump 10 to 12 hours per day. Those opportunities need to be pursued aggressively by NIH.

The use of enhanced fetal hemoglobin could end the need for blood transfusion and, therefore, the need for removing iron from the body.

But a vigorous research effort must be made. Opportunities exist to find ways to measure the iron accumulation to the organs more effectively. Today Michael has to have a needle stuck through his abdomen into his liver to get an accurate measurement, a painful and costly procedure. There is promising new technology called a superconducting quantum interference device, or SQUID. But there is only one such machine in existence in this country.

There are more areas of important research, Mr. Chairman, in my written statement, but I want to be very clear on my basic point: All of us affiliated with Cooley's Anemia Foundation are very supportive and grateful for the research that has been conducted at or funded by NHLBI and NIDDK over the years. We know that it is directly responsible for the extended life span of our children. We also know that we are on the cusp of many breakthroughs. Important advances can be made in treatment for these kids.

My dreams for Michael are no different than any other parents' for their children. I want him to grow up happy. I want him to experience all that life in our great country has to offer. I do not care if he is a doctor or a Congressman or an auto mechanic, so long as he has the same opportunities to succeed that everyone else has.

The creation of a network of collaborative clinical centers is the first step in assuring that successful outcome.

Thank you for your consideration.

[The prepared statement of Joseph Giammalvo follows:]

[Pages 1818 - 1825--The official Committee record contains additional material here.]

Mr. Porter. Mr. Giammalvo, thank you for your testimony.

Has NIH told you why they are not proceeding with this?

Mr. Giammalvo. I have to field that to Ms. Cioffi.

Ms. Cioffi. They think that the patient population is too small, and actually, I don't think that they recognize all of the recommendations out of the Special Emphasis Panel are really ready for development. Any number of them can be explored at this time. In particular, fertility issues, psychosocial issues, the iron measurement issues, they are all very ripe for proceeding with a collaborative network.

Mr. Porter. We will follow up with NIH and stay in touch with you regarding all of this because obviously we want to give Michael and all the Michaels the greatest opportunity possible for them to live normal lives.

Mr. Giammalvo. Thank you.

Mr. Porter. We thank you for your testimony.

Mr. Giammalvo. Thank you.

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WITNESSES

J. ALFRED RIDER, M.D., PH.D., CHILDREN'S BRAIN DISEASES FOUNDATION

MICHAEL JOYCE

CHRISTOPHER CAMPBELL

Mr. Porter. Alfred Rider, M.D., Ph.D., President; Michael Joyce, Trustee; and Christopher Campbell, Trustee; testifying regarding Children's Brain Diseases.

Dr. Rider, it is good to see you again, sir.

Dr. Rider. I am J. Alfred Rider, President of the Board of Trustees of the Children's Brain Diseases Foundation. This will make the 21st time since 1978 we have been here, and there have been tremendous progresses made in the research on Batten disease. When we first started in 1978, nobody had heard of the disease. There was no treatment, no research going on, and so forth.

As a direct result of this committee's actions, finally, in 1991 to make specific dollar amount recommendations, significant research has been done. Batten disease, as I have told you before, is the most common neurogenetic disease in children, about 300 children born a year. There are over 440,000 carriers in the United States.

In 1995, just to show you how fast things progress, the gene defect and the early infantile form of the disease was localized on chromosome 1p32.

In 1996, the gene for the classical infantile form was localized on chromosome 11p15, and the gene for the variant of the late infantile which lies on chromosome 15q21-23.

In 1997, a group led by Dr. Pete Lobel, using a much faster novel approach of looking at lysosomal enzymes instead of

concentrating on which of the 100,000 genes are defective, discovered the molecular basis for the late infantile form of Batten disease by identifying the single protein that is absent in this disease.

It is now possible to make an absolute definitive diagnosis and determine carriers in all three childhood forms by a simple blood test, and to prevent the disease by genetic counseling, including in vitro fertilization.

In spite of this, in 1997 the NINDS spent \$2,838,000, which was 13 percent less than in 1994. So we had great impetus growing, and now we hope that this trend won't continue.

If we can continue with that research, we should be able to get specific enzyme therapy which will be able to treat these diseases. We feel that the diseases drain our national resources by approximately \$712,000,000 a year.

Our specific recommendations are these: Although there have been four significant breakthroughs with regard to gene localization in Batten disease and the identification of the single protein that is absent in the late infantile form, we were disappointed that the funding for 1997 was approximately 13 percent less than 1994. As you know, the budget has continually increased at the NIH every year. Consequently, we would like to suggest that the following wording, similar to what we used last year:

``The committee continues to be concerned with the pace of research in Batten disease. The committee believes that the institute should actively solicit and encourage quality grant applications for Batten disease and that it continue to take the steps necessary to assure that a vigorous research program is sustained and expanded. The committee has requested that \$3,470,000 within the funds available to the NINDS be spent on Batten disease research. This represents an average yearly increase of 4.1 percent since 1994. This will allow for \$2,800,000 for continuation and renewal grants and \$631,000 for new grants.''

I would like to mention, I have Michael Joyce here and his wife, Rosemarie. They are parents of a set of twins, Ian and Joey, who have the late infantile form of Batten disease. I think they have been here since you have been chairman the last several times. I am happy to say they are still alive and doing as well as can be expected because they get superior nursing care, and there is where tremendous expenses come in.

I thank you very kindly.

[The prepared statement of J. Alfred Rider, M.D., follows:]

[Pages 1828 - 1838--The official Committee record contains additional material here.]

Mr. Porter. Well, Dr. Rider, I have been on this subcommittee for 17 years, and you have been coming here longer than I have been here. You have been a wonderful, strong advocate, and we have attempted, I think, to listen very carefully to what you have to tell us. You know that we don't direct NIH to do things, but sometimes we can lean a little bit. I was not, frankly, aware that they had been spending less

on this. I am going to look into it personally and find out why and assure you that we will do everything we can to continue to put this at a high priority at NIH.

The Joyce family and the boys have touched our hearts many times, and we want to respond, obviously, for them and for all the children that suffer from this terrible disease. So we will do our best, and we just want to say that your advocacy has been absolutely wonderful, and we look forward to seeing you-- look forward to progress.

Thank you, Dr. Rider.

Dr. Rider. As a transplanted Illinoisan to San Francisco and knowing that you are from the Northern Jacoby area, I came from Riverside, Illinois, so it is a pleasure to testify.

Mr. Porter. Very nearby, right.

Thank you very much.

Thursday, February 5, 1998.

WITNESS

BOBBY SIMPSON, AMERICAN REHABACTION NETWORK

Mr. Porter. Bobby Simpson, Director, Rehabilitation Services, testifying in behalf of the American Rehabilitation Network.

Mr. Simpson. Thank you, Mr. Chairman, members of the committee. It is indeed a pleasure to be here. I am Bobby Simpson. I am the commissioner of Arkansas Rehabilitation Services, the State vocational rehabilitation agency in the fine State of Arkansas, from which Mr. Dickey is a distinguished member of this fine subcommittee. Today, I am pleased to be representing and testifying on behalf of the American Rehabaction Network, the membership of which is composed of thousands of dedicated men and women who are vitally interested in and supportive of the public vocational rehabilitation of persons with mental and/or physical disabilities.

This particular network is the largest and only professional development and advocacy organization whose sole purpose is to support the public service delivery system of services that enables and ensures that hundreds of thousands of persons with disabilities have the opportunity to take their place in a competitive employment situation as taxpaying members of society and have an opportunity to live independent, productive lives. That is the whole focus of our testimony today, is to urge adequate Federal monies be appropriated under Title I of the Rehabilitation Act in order that thousands of unserved and underserved Americans with disabilities might take their place in meaningful, high-quality jobs.

You have seen, I think, already this morning, the indication of the definite need for an expanded service delivery system of vocational rehabilitation services for people with disabilities by the individuals who have already testified. You have seen young people who, with the right kind of medical support and services, are going to grow up into adolescents and young adults. They need a strong State-Federal partnership of public vocational rehabilitation services in

order to get the kind of training and the kind of skills they need in order to prepare for and enter the workplace and become productive, independent, taxpaying members of society.

Many of these young people you saw in here will end up having the opportunity to work if our program is adequately funded. To that end, our members are urging the Congress to appropriate \$3,000,000,000 in fiscal year 1999 for vocational rehabilitation services under Title I of the Rehabilitation Act.

Currently, the administration's budget has a proposal for \$2,300,000,000, approximately, for Title I of the Rehabilitation Act. That is just a few pennies above the mandatory cost-of-living increase that is contained within the program.

Mr. Chairman and members of the committee, it has been extremely frustrating to me, as a person with a disability, who has grown up in this system, who would not be working today were it not for the public vocational rehabilitation system, and now one who has had the opportunity to live independently, to live in my own home, to drive my own vehicle, the privilege to pay taxes, which I consider to be a privilege, considering that well-intended medical professionals indicated I would spend my life in a nursing home instead. All that has happened because of the strong public vocational rehabilitation program.

Now that I administer a program in a State agency and my counterparts across the entire country--hello, Mr. Dickey. It is such a pleasure to see you, sir.

Mr. Dickey. Hello. How are you doing?

Mr. Simpson. I am good. I am good.

I am just frustrated, to tell you the truth. I am tired of turning people away with disabilities saying we can't serve you because we don't have enough money to assist you to get the basic services you need to enter the world of work. I am tired of telling folks with disabilities who know they have a disability, they have a need for rehabilitation services in order to go to work, I am tired of telling them, I am sorry, but your disability is just not severe enough because our Federal laws and Federal regulations say if we don't have enough money, we can only serve those with the most severe disabilities.

Our folks in Arkansas, they don't care whether they are classified as severely disabled or non-severely disabled. If they have a disability, they want some assistance from us in order to enter the world of work. And in order for us to be effective in our program and to deliver the kinds of services that people with disabilities need, it is essential that we receive an increase above the basic cost-of-living increase that we find in the administration's proposal.

So, therefore, Mr. Chairman and members of the committee, I don't really want to take a lot of your time, but I really want to re-emphasize the fact that with the public vocational rehabilitation system having been around for some seven decades and transformed itself, streamlined our systems over the years, we feel that we have really positioned ourselves to work very effectively with people with disabilities, with business and industry, with the increasing number of people who will be coming to us from the welfare-to-work initiatives. We are well

positioned to work effectively and put people with disabilities to work if we have the resources to do so.

I am very pleased with the program we operate in Arkansas and with the State-Federal partnership that we have consisting of individualized, systematic services, leading to employment opportunities. We have even been able to show the welfare-to-work folks how we do it in rehabilitation in terms of a systematic plan that results in a positive employment outcome.

So, Mr. Chairman, again, I urge the committee to seriously consider appropriating \$3,000,000,000 for the public vocational rehabilitation program, Title I, in order that we can go on down the road of providing the kinds of services that enable people, like those you saw in this room today, to prepare for and enter the world of work and become productive, independent, taxpaying citizens.

I greatly appreciate the opportunity to appear before this body again and to see our champion and hero in Arkansas, Congressman Jay Dickey.

Mr. Dickey. Did you hear that, Mr. Chairman?

Mr. Porter. The Chair yields to Mr. Dickey, the hero.
[Laughter.]

Mr. Dickey. I apologize for being late. I wanted to introduce Bobby, but I think the best introduction was just hearing him talk. I think one of the gifts that Bobby has, Mr. Chairman, is that he is an advocate and that he fights for people who he sees want to improve. And in Arkansas, his office, his place of business, is right across the street from our office, and we know for sure that Bobby is exhorting people, that he is not letting this become just a distribution of money, but it is a distribution of opportunity. Bobby Simpson is one of the heroes, and I want to put my--whatever--little influence I have behind this man's testimony. Bobby, I want to tell you, I want to thank you, and I want to show you my thanks by trying to do what you have asked to get done in this committee.

I wish I had more influence, particularly with that man right there, you see. If I had more influence with him, I could do more.

Mr. Porter. Don't every believe that Jay Dickey doesn't have a lot of influence.

Mr. Simpson. Yes, sir. I know he is the master of understatement sometimes.

Mr. Dickey. Thank you, Mr. Chairman.

Mr. Porter. Mr. Simpson, let me first apologize for not stating correctly that it was Rehabaction Network. My notes say that, but it is run together, and I thought it was a misprint when I first looked at it and I read it as ``rehabilitation.'' It is Rehabaction, and I apologize.

Mr. Simpson. No problem.

Mr. Porter. Secondly, because you are asking for substantially more money than the President's budget has suggested, you get Sermonette No. 1.

Mr. Simpson. Yes, sir.

Mr. Porter. And that sermonette goes something like this: We can only do as well as the resources that we have to work with. And there are two parts to this process. One is here at the appropriations level, where we look at priorities and try

to sort them out in a fair and equitable way. And the other is at the Budget Committee where they give us the allocation of funds that we have to work with. So we urge all--and this is not just for you this is for everybody in the room. We urge all of you to not only participate in our hearings and impact our process, but to also participate in the budget process, because what they give us to work with determines largely what we can accomplish.

Mr. Simpson. Absolutely, Mr. Chairman. We will certainly do that. I appreciate your time.

Mr. Porter. Thank you.

[The prepared statement of Bobby Simpson follows:]

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

[Pages 1843 - 1851--The official Committee record contains additional material here.]

Thursday, February 5, 1998.

WITNESS

JACK LAVERY, LUPUS FOUNDATION OF AMERICA

Mr. Porter. Jack Lavery, Chairman, Lupus Foundation of America, testifying in behalf of the foundation, and we are pleased to welcome our colleague, one of our favorite people in Congress, Congresswoman Carrie Meek, to introduce him. Carrie, it is nice to see you.

Mrs. Meek. Thank you very much, Mr. Chairman. It is always good to come before you and the committee today as last year, I am here to introduce a man I think is a very profound person, Mr. Chairman, one who has displayed over the years the sensitivity to this disease which doctors have not been able to find the cause nor the cure, and that is lupus.

Mr. Dickey. Excuse me. I am Jay Dickey from Arkansas.

Mrs. Meek. Hello, Jay. I just saw you this morning.

Mr. Dickey. I am on this committee, and you have my vote. You understand that?

Mrs. Meek. Good, good. Thank you.

Mr. Lavery, Mr. Chairman, brings a new dimension to testimony before committees. He has had a background in the business world and the corporate arena, and he has served as volunteer in the movement to help us receive adequate funds for lupus.

I just want to say that to introduce Jack Lavery is to introduce a man who has worked so hard with lupus throughout this country, and he does his full-time job. He is a senior vice president of Merrill Lynch & Company, and he represents the Lupus Foundation.

I won't take a long time, Mr. Chairman, because you know I always ask for money, you always give us a little tad, but we are happy for that. Whatever you give we are happy for it. I want now Mr. Lavery to come up, and you will agree with me that

he is a very, very outstanding person.

Thank you.

Mr. Porter. Thank you, Congresswoman.

Mr. Lavery?

Mr. Lavery. Thank you very much, Congresswoman Meek, for that nice introduction.

Good morning, Mr. Chairman, members of the committee. In introducing myself, I am Jack Lavery, and my principal role in life is as senior vice president of Merrill Lynch & Company. But I am here today in my volunteer capacity as chairman of the board of the Lupus Foundation of America, therefore representing the between 1.4 and 2 million Americans that our own marketing research study done by the Lupus Foundation of America believes to be the actual incidence of lupus in this country. One of those 1.4 to 2 million Americans is my own daughter.

The Lupus Foundation of America is a national advocacy organization. It is pursuing finding the cause and the cure of lupus. It is also involved in providing patient services and a great deal of educational information with regard to lupus.

Lupus, in a nutshell, is an autoimmune disease. The body, in effect, turns on itself, attacking many organs in the body, and quite randomly.

The challenge is, because the cause and the cure aren't known, the side effects of dealing with this disease, the side effects of the current treatments, can be every bit as devastating as the disease itself. The principal medication to deal with the symptoms relate to steroids, but protracted use of steroids causes osteonecrosis, or bone death. And when lupus is active in the kidney, the principal medication that current research makes available is cytoxan, a highly toxic chemotherapy drug, the side effects of which are high risks of sterility, bladder cancer, and lymphoma later in life.

Lupus is a woman's disease, by and large. It doesn't mean a lot of men haven't been affected by it. Terrell Davis, the star of the Super Bowl, his father passed away from lupus recently. Julius Irving, the star basketball player, lost a brother to lupus. So it is not uniquely women, but 90 percent of the people who have lupus are women.

The relative incidence of lupus is much greater among minority women. Specifically, Hispanic Americans, Asian Americans, and African Americans are more likely to have lupus than are Caucasian females.

I want to thank this committee, particularly you, Mr. Chairman, and all the committee for your leadership in ensuring the continuation of immune system research at the National Institutes of Health and NIAMS, the National Institute of Arthritis, Musculoskeletal and Skin Diseases.

I urge your support, very important support, to fund NIAMS at the \$315,900,000 level recommended by the Ad Hoc Group for Medical Research Funding and supported by the NIAMS Coalition.

NIAMS has already started moving on creating scores, SCORs, Specialized Centers of Research, with regard to lupus, and NIAMS is also supporting the creation of a lupus registry of patient information throughout the country.

In November of 1997, we had a flagship conference here in Washington, D.C., supported by the National Institutes of

Health. This conference was also cosponsored by the Lupus Foundation of America and by the SLE Foundation, standing for systemic lupus erythematosus, the technical name of the disease, the largest single chapter of the Lupus Foundation of America. And that research forum was a landmark scientific event because it brought together private and public sector folks, research people. Collaboration, we believe, is the key to finding the cause and the cure of lupus.

That research forum in November of 1997 will result shortly in output in the form of a definitive white paper, the blueprint for the cure, because, Mr. Chairman, I must say, that lupus is the prototypical autoimmune disease. If we are able to unlock the keys to find the cause and the cure of lupus, the beneficial consequence will not uniquely be to lupus patients alone, but also to folks with myasthenia gravis, Crohn's disease, multiple sclerosis, grave's disease, or any other autoimmune disease that I have neglected to mention.

My own daughter got it at age 13. It wasn't correctly diagnosed until she was 19. Typically, it is incorrectly diagnosed as juvenile rheumatoid arthritis in the early stages. She has had the osteonecrosis consequences. She has had core decompressions, drilling of her left hip, right hip, left knee, right knee, and left elbow, to try to create renewed blood vessel growth. It failed in the hips. She has since had bilateral hip replacement. She is only one example.

But I am inspired by her courageous fight. She has an optic neuritis, a lupus flare in the central nervous system that caused her permanent blindness in one of her eyes. But she is still going forward, teaching high school English. She is battling this disease, but we need a great deal of help with regard to research. It is absolutely critically important. We have started the ball rolling with this tremendous scientific conference that the NIH, SLE, and LFA all combined upon in November here in this city, and, again, I want to thank the committee for its time and attention this morning.

[The prepared statement of Jack Lavery follows:]

[Pages 1855 - 1860--The official Committee record contains additional material here.]

Mr. Porter. Mr. Lavery, thank you for not only your testimony this morning, but for your tremendous commitment to seeing this research through to improve the lives of all people afflicted with the autoimmune diseases. We very much appreciate it. We are going to take your words to heart and do the very best we possibly can to put biomedical research and research on lupus in a high priority.

Mr. Lavery. Thank you very much, Mr. Chairman.

Mr. Porter. Thank you for coming here to testify.

The House has two votes on. We will be forced to take a brief recess until we can cast those votes and then resume our schedule. The subcommittee stands in recess.

[Recess.]

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Thursday, February 5, 1998.

WITNESS

JOHN D. AQUILINO, JR., PRIVATE CITIZEN

Mr. Porter. The subcommittee will come to order.

Our next witness is John D. Aquilino, a private citizen, testifying in his own behalf.

Mr. Aquilino.

Mr. Aquilino. On behalf of my son, Johnny, his brother Tommy, and my family and myself, I would like to thank the chairman for allowing me to testify today before you.

My son, who is having a constant struggle with phonics, couldn't be here today. I didn't want to take him away from school. I didn't want him to miss any more.

I am here primarily to dispel the myth that heart disease is a condition confined to people my age and older. It is not. Heart disease is America's number one killer of all of our people. It is the cause of America's most common birth defects. I am here also to plead for increased funding for the National Heart, Lung, and Blood Institute and, in specific, its heart program.

Congenital heart defects are the major cause of birth defect-related infant deaths. They strike 32,000 newborns each year, and they kill more than 2,300 babies before their first birthday. Nearly one million children, like my son, bear the consequences of those defects.

My son is almost 8. He plays tee-ball for St. Jerome's School in Hyattsville, Maryland. He is the oldest surviving patient at Washington, D.C., Children's Hospital, and perhaps the east coast, with hypoplastic left heart syndrome, which basically means his left heart's major pumping chamber, the ventricle, is missing.

At age 2 days, Johnny spent 6 frantic hours in Children's Hospital's emergency room before his condition was diagnosed. His heart and lungs stopped twice, and twice they brought him back. One week later, he underwent the first of three open-heart surgeries he received before he was 4. To the degree he can, Johnny has also given of himself for biomedical research. He participated in a program to develop treatment--I am sorry, but all my life, when I talk about it, I have the same reaction--for RSV, a condition that debilitates young heart and lung patients.

A few years before Johnny's birth, one of my dearest friends, B.J. Pino of Home, Pennsylvania, lost his first son to hypoplastic left heart. Barely 3 years before Johnny's birth, little or nothing could be done for infants with this condition. Thanks to the research funded in great part by this subcommittee, and the efforts of a great number of men and women, my son is alive and able to suffer the rigors of second grade.

I am here because Federal funding for the Heart, Lung, and Blood Institute decreased by 5.5 percent in constant dollars from 1986 to 1996. I concur with the American Heart Association's recommended funding of the institute at \$1,825,000,000. I also join the American Heart Association and

Research!America in asking that NIH funding be doubled in 5 years.

The main reason I am here is the fact that I love my son. Animal-based biomedical research gave me my son. Over the next 5 or so years, if you and the Congress allow it, the ethical use of organ cloning research, if you allow it to continue, he may have a new heart made from his own DNA.

When my son's condition was diagnosed, he lay connected to a tangle of tubes and monitors, looking as sad as any human can be. The doctors asked if we wanted him to live. That was the single hardest question anyone could ask a new parent. It was not hard to answer. From the bottom of my heart then and from the bottom of my heart now, I answer yes. Yes, I want my son to live.

Yes, I want the children of fathers and mothers from Hyattsville to Harare, Zimbabwe, and all points in between to live.

From my heart and from the love I have for my son, I want to thank you for your help in allowing men and women of science to be able to do the research that gives the gift of life to children like my son. I only ask that you please make this America's first priority.

[The following statement of John Aquilino Jr., follows]

[Pages 1863 - 1869--The official Committee record contains additional material here.]

Mr. Porter. Mr. Aquilino, we are doing everything we can to make it the first priority. I think it is the first priority. I think if people in the Congress could have the chance to listen to people like you, they would understand much more how much these problems touch American families, and they would push it to a higher priority. So your advocacy here is very important. I wish the whole subcommittee were here to hear you.

Obviously we need the resources in the jurisdiction of the subcommittee to make the kinds of increases that we want to make. And I am going to say this to this panel, too. This is not just to you, but to all who are concerned about this. I think it is going to be very difficult this year, because the budget isn't yet in balance, to get the kinds of increases that will start us on a 5-year path to doubling the budget for NIH. Yet, I think the prospects in a very good economy are that we can start on it next year when the budget is in balance, if we have the kind of support from the American people that I think we need to have. In other words, we need to have this process impacted, not just our subcommittee, where we do put it at a high priority, but the whole Congress and particularly the budget process, which gives us the money that we have to work with.

So I think it depends on how much we can get into the minds of the American people that this is something that we can do if we want to do it, and that we ought to do it. In other words, every Member of Congress has to have it in their mind that their constituents want them to do this. If we got them there, the job would be done.

So I say often that we don't make policy here in Washington, we merely ratify what the policies of the American people are. And to the extent that they can communicate those ideas to Congress, Congress is going to respond. So your advocacy is terribly important on this, yours and so many others, and to the extent that you can impact as broad a population as possible, that is what is going to make the difference, as it always does.

Thank you for being here to testify. We are going to do the best for your son, John, and all other kids that are suffering the same way and do everything we can to provide the resources to NIH that they need to address these kinds of problems.

Mr. Aquilino. Thank you, and I will do what I can from my point.

Mr. Porter. I know. You are doing it.

Mr. Aquilino. Thank you.

Thursday, February 5, 1998.

WITNESS

DONALD S. COFFEY, PH.D., NATIONAL COALITION FOR CANCER RESEARCH

Mr. Porter. Donald S. Coffey, Ph.D., member, Board of Directors, the National Coalition for Cancer Research.

Dr. Coffey?

Dr. Coffey. Chairman Porter, I am going to discard my speech--it is in the record--and just tell you that you are a champion of trying to make health funds available, and we salute you. And we recognize the problems you face in today seeing the people that suffer. You see this every year, and this is my first time. But I see it from the cancer standpoint, and it is the same thing we see here.

What I would like to share with you is I represent the National Cancer Coalition for Research, and this is 22 organizations. It is not-for-profit, and it represents about 55,000 physicians, nurses, and many thousand patients, 40,000 children, 82 cancer centers and hospitals, and so it is a large coalition for cancer research. I am president of the American Association of Cancer Research, which is a separate group of researchers. But I am heretoday with the president, Carolyn Alders, sitting here, the president of this organization.

Let me just start by first telling you that what we are trying to do is reach out to the House and Senate Budget and Appropriations Committees, because we recognize only the pot of money they give you to work with. So we are working hard at that level, and we are encouraged by what we see.

But from my heart, let me tell you what I really see. I was a young engineer with Westinghouse on October 27, 1957, and we had nothing going in space, and I saw the Russians fire up that satellite. And the money poured in, and I just could not tell you. We went from worrying about whether we were going to hit Russian residential areas when we landed on the moon to having a car up there in no time flat. Of course, as you know, our space efforts are about six times what cancer research is, and we know that the funds have to be somehow from the American people through Congress redistributed here.

Now, we are not against space. We are not against military. We are not against any other diseases. So what we are pushing for is a doubling of the NIH funds overall. We don't want to be in a war against all the people suffering in the United States, and we push the budget as seen there.

The great moment in my life occurred when I stood at the Children's Hospital in Baltimore and watched five dump trucks haul 75 iron lungs to the trash dump that will never be used for polio, after having seen some of my classmates in iron lungs in Bristol, Tennessee, when I was a kid. I know research can do this, and we have cured six cancers. People say, When are you going to cure cancer? We have cured testicular cancer, which was devastating. We get a lot of lymphomas and leukemias in children, and there has been tremendous increases. So we can do this.

The big ones that are tougher--lung, prostate, colon--these are the ones we are having trouble with. I cannot tell you what is out there. We have made more progress in cancer research than has been made in the computer. We have got to bring that now to where it impacts on the patient, the same way we did on those others. And it can happen.

Now, what disturbs me is that every time we put in ten grants of these young people putting in grants and things, seven of those do not get funded; only three get funded. And you are aware of that. Actually, it is 23 percent. So we have never had a war on cancer. The entire act that we do as far as supporting this wouldn't buy two big Stealth bombers. They cost more than the whole cancer act. So we recognize it is time for America to declare war.

Now, President Nixon--it was a bold step forward--declared this war, but it didn't follow that the money followed that. So we went from funding it at 42 percent when he declared the war down to 18 percent over the next few--now we are up to 23.

We think that young people who have a lot of debts for their education, they look up and they only have a 23 percent chance of being funded, and they have wives and children. They are falling out by the droves. And with the medical care changes and managed care, it is devastating.

So what we would like to do is three things to call upon, please, sir, is to support the resolution, both in the Senate, and you have certainly been on that. That is like asking me to support eating with my obesity. You are a man who has really supported this. But I am asking you and your committee to support that resolution.

The second thing is the tobacco allotment. I cannot tell you the devastation that this has done to the American people, and you know that. But when you see it up close, it is beyond belief. The number of people dying in this country every day, every day from cancer, would fill five Boeing 747s crashing with everybody on board. Now, if the people knew that, that five Boeing--everybody has to die, but you don't want to die from cancer. Five of these go down. Two of these Boeing 747s are brought down because of smoking. We just cannot have this sort of thing going on. And now none of the money is going to go for research.

We are asking for Congress and these allotments to figure out how to put some of this into cancer research and some of it

into NIH research, and to have it go through the regular peer reviews where it will have high quality.

So we salute you, sir, and your committee, and we are working as hard as we can, and we hope that the big changes we see in the spirit towards medicine will carry over for all these people in this room.

Thank you, sir.

[The prepared statement of Donald Coffey follows:]

[Pages 1873 - 1885--The official Committee record contains additional material here.]

Mr. Porter. Dr. Coffey, you have raised a lot of very important issues. You get Sermonettes 2 and 3 on these, I am afraid.

The first one is that if you look at NIH throughout its history, 50 years of history, the average rate of increase over that period of time in real terms--in other words, above inflation--is about 3 percent. So the Congress has made a continuous--and administrations have made a continuous commitment to increasing the funding for biomedical research, and even in the last 3 years in very tough budgetary times, it has been put ahead of almost everything else, and we are actually having an increase that is in excess of 3 percent, even in this time frame.

The difficulty isn't that we are not giving it more money. The difficulty is that there is more good science to be funded. And, therefore, as you say, there are fewer chances to get it funded. There simply is so much there.

What that tells me is exactly what it tells you, that we have got to dramatically increase the funding because we are falling behind even though we have been supporting it very strongly. And that is why we need to double the research.

Sermonette No. 3 says, however, I worry--and this is a strategic, political question. I worry that if we don't increase funding for all research funded by Government that we will set one type of research against another. And I don't want that to happen.

Mr. Coffey. Absolutely not.

Mr. Porter. While I think that biomedical research, because it is a direct effect on the lives of human beings, is the highest priority, I believe that we also ought to make a commitment to increasing funding of basic research in all areas.

Mr. Coffey. We agree with that.

Mr. Porter. And that they should come together, because if they won't, they will fight one another, and that will make it much more difficult.

Your point about clinical research and what is happening to our academic medical centers in this new environment of health care delivery is a very good point and something we must worry about. This subcommittee can't do a lot about that, but it can do something. But I think it is a tremendously important point. This is where our resources, our intellectual resources lay, and they are under siege because of the changes to managed care

that have been the hallmark of our delivery system over a long period of time.

The tobacco tax, I sure agree with you, those are funds that, by anyone's logic, ought to go to research. We ought to raise the tax simply to get young people off of being hooked so that they won't be in the clutches of the industry. That lies ahead, and that may end up being a part of the research portfolio. No one quite knows at this point.

My own prediction is that nothing will happen on the tobacco settlement, but there is some talk--you have to consider this in the context--that a tobacco tax will be raised in order to use the funds to bring greater tax equity in other taxation programs, like the marriage penalty that is in our income tax system, and greater relief for families. If that is done, it will be revenue neutral and won't have any effect on the budget, but it will also make it much more difficult in the future to raise tobacco taxes for research purposes, because we will have pushed the tax up so high that you begin to get to the point of diminishing returns.

All the points you make are very salient points, things that we have to worry about. I thank you for coming to testify.

Mr. Coffey. Just let me share one last thing, if I might, with your permission.

Mr. Porter. Surely.

Mr. Coffey. One of the things that has horrified us as scientists is discovering in the last 2 years that the lungs of former smokers are badly damaging to their DNA, that is, it is permanent and not correcting itself. And over half of cigarette smoking cancers are occurring in former smokers. We didn't realize that this is not coming back to normal like everybody thought. And they have to pay for this. Somebody has to----

Mr. Porter. Now you are getting personal, as a former smoker----

Mr. Coffey. Yes, I smoked, too.

Mr. Porter. How long----

Mr. Coffey. Even 20 years out you have a 1.5- to four-fold increase, and it is not correcting these damages, and we have to understand----

Mr. Porter. How about 30 years out? [Laughter.]

Mr. Coffey. You are better off. Thank you, sir.

Mr. Porter. Thank you. I appreciate it very much.

Thursday, February 5, 1998.

WITNESS

RALPH G. YOUNT, PH.D., FEDERATION OF AMERICAN SOCIETIES OF EXPERIMENTAL BIOLOGY

Mr. Porter. Dr. Ralph Yount, President, Federation of American Societies for Experimental Biology, testifying in behalf of the federation.

Dr. Yount?

Dr. Yount. Thank you, Mr. Chairman.

I am Ralph Yount, professor of biochemistry at Washington State University, and I am a basic scientist who works on the mechanism of muscle contraction. This year I am serving as

president of the Federation of American Societies for Experimental Biology, which is commonly known as FASEB. This is the largest organization of life scientists in the United States and has over 52,000 members and does the basic research that we hope is going to underpin the diseases that we have been hearing about today, the cures for the diseases we hear about today.

Like our previous two speakers, I am here to encourage the doubling of the NIH budget for fiscal year 1999, realizing the difficulties you face in doing this--I am sorry, a 15 percent increase in the NIH budget in the next fiscal year, with the idea that we can double it in 5 years.

I think we are also very pleased with the budget request for NIH submitted by the President this week and his strong statement in favor of biomedical research that he gave in his State of the Union address, and we are hopeful that Congress can go even further, but we also recognize this is the first time since the war on cancer Dr. Coffey talked about that a President has aggressively supported funding for the NIH, I think due in large part to your leadership and this subcommittee.

It appears that finally the President and the Appropriations Committees--both the House and the Senate, and both the Republicans and the Democrats--now agree for a large increase for NIH. We think this goal is fully justified and achievable, and we stand ready to work with you on achieving it.

I think the other thing is that NIH has fostered the development of biomedical research which is the envy of the world, and the scientific investigations they have supported have given rise to the biotechnology industry, fueled the activities of the pharmaceutical industry. They have altered the daily course of health care of every American. And they are even changing the nature of agriculture. So the list of discoveries is remarkable, and I just wanted to give you two examples of these.

One is that NIH-supported research led to the development of so-called DNA chips, which are defined fragments of DNA on computer chips, which promise to revolutionize the detection of gene-based diseases such as breast cancer.

A second example is that NIH researchers developed a crucial enzyme called telomerase, which plays a critical role in cancer and normal growth and likely in the fundamental process of human aging.

The tragedy of these examples is that many more breakthroughs are possible, and they remain elusive due to insufficient resources. As Dr. Coffey alluded to, this year NIH will fund about three of ten proposals approved by study sections, but when you look at young investigators, it is substantially less. It is slightly more than one in ten. I can tell you as a researcher, these are discouraging, and particularly for young faculty members starting out in research. These unfunded applications and the unfunded researchers we think are the best argument for increased support for NIH.

We also have a view on how these new monies can be best utilized, and while we don't have--these are not etched in

stone, we would like to use these as a starting point for your committee and for NIH to consider. They are in seven areas.

First, fund increased numbers of investigator-initiated research grants selected through the competitive review by scientific peers;

Second, adequately fund research projects by increasing the average size of grants;

Third, raise stipends for pre-doctoral and post-doctoral trainees to a living wage;

Four, modernize the research infrastructure, including facilities, instruments, and clinical research support mechanisms, the things that Dr. Coffey was talking about;

Five, support a wide variety of new scientific partnerships, including more extensive direct support by NIH for relevant studies in chemistry, physics, mathematics, and computational science--the idea that you were just discussing in terms of supporting other areas of science;

Six, develop and support mechanisms for more rapidly translating research findings from the laboratory to the patient;

Finally, increase the average length of grants to create a more stable research environment.

These are our suggestions to you as you begin this difficult task of deciding how best to invest the increased resources for biomedical research that we all hope can be found. We have made other policy recommendations in the formal report which we hope you will review carefully.

In conclusion, as we have heard this morning, I believe this point in time is the best opportunity in a generation to expand our Nation's efforts to improve America's health using the tools of science. We recognize the challenge this represents, and we pledge to use all our resources to convince Congress to give this subcommittee the budget allocation it will need in order to make our mutual goal a reality.

Thank you very much.

[The prepared statement of Ralph Yount follows:]

[Pages 1890 - 1896--The official Committee record contains additional material here.]

Mr. Porter. Dr. Yount, if I can comment just a second on the President's budget, I also was encouraged by what he had to say about increasing research funding. His proposal, however, is to increase it 50 percent over 5 years, which is not, I think, enough to close the gap on the number of good science proposals being funded, in other words, increasing the percentage. I think that is going to fall way short of the mark.

However, this is the first President who has made that commitment. The President's budgets in the past 3 or 4 years have been way short of what Congress has provided, and so I think all of us have been encouraged that it was mentioned as a high priority.

The difficulty with the President's budget is that spending, particularly the discretionary spending, depends upon

a revenue stream that is very unlikely to occur any time soon, and maybe not at all. And the proposed increases have about \$100,000,000,000 of new revenue over 5 years behind them. And I don't think that we can count on those revenues being part of this budget as the House takes up and the Senate takes up the President's proposals. And that means that the spending in--I am not talking just about biomedical research. I am talking about everything under the jurisdiction of this subcommittee that is going to make getting the kind of allocation we need much more difficult if we are going to reach the goals that have been mentioned by so many witnesses.

And you said very early you are going to impact the budget process as well, and that is exactly what I think we need to do.

Mr. Yount. Right. Well, we stand ready to work with you on this, and we realize the difficulties in finding the funds for this kind of increase.

Mr. Porter. Thank you, Dr. Yount. We very much appreciate your testimony.

Thursday, February 5, 1998.

WITNESS

JERRY LAWRENCE, FEDERAL MANAGERS ASSOCIATION

Mr. Porter. Jerry Lawrence, President, Federal Managers Association, Social Security Administration Conference, reporting the Federal Managers Association.

Mr. Lawrence.

Mr. Lawrence. Thank you, Mr. Chairman. My name is Jerry Lawrence, and I am President of the Federal Managers Association, Social Security Council. We represent more than 1,000 Social Security managers who work in our program service centers, our office of central operations, and our office of hearings and appeals.

And, at the risk of getting sermonette number four, I will avoid that. I have never testified before Congress and we are not asking for more funding than is in the President's budget. We do have some rather passionate feelings about how the funding is going to be spent by the Social Security Administration and we do think that the Administration can do more in terms of taking a more modernized approach in terms of the way it delivers service to the American public.

Collectively, I guess our average age is about more than 50 and we have, on an average, more than 25 years of service, within the Social Security Administration. We feel that the Social Security Administration is on a precipice of moving forward with new technology and with a lot of advancements but we think that the agency has to come to grips with the way it delivers service to the American public.

Essentially, the way we are operating is the way we operated when I first started working for the Social Security Administration. We have not taken advantage of the technology and we have not really moved forward.

There have been a number of reasons why we have not done that. Some are very valid, others can properly be attributed to

internal politics within the agency, and we think it is time with this Fiscal Year budget to take a serious look at the way we are doing business and the way we present service to the American people.

Over the last five years, our 800-number has grown by 500 percent. Just as an example, in our Kansas City Social Security Office, that office took about 500,000 telephone calls in 1992. By 1997, they had more than 2.5 million telephone calls. Clearly, the American public wants to do business with us using the telephone and we want to be able to serve the American public that very same way.

We have the capacity right now to take one telephone call from a number of people and resolve most of their issues within that one telephone call. But because of internal SSA policies and a reluctance to move into the new technology, in many instances what we are doing is we are making appointments for somebody to call those people back, either several weeks or several months hence.

From our perspective, as experienced managers working for the agency, we really do not think that that is the best way to serve the American people. We also have some very strong feelings about the quality of our work product and recently a number of periodicals, Money Magazine, has highlighted some of the issues that we are being confronted with right now in terms of our service delivery.

We think that the agency feels the pressure of trying to stay on top of their work loads. In our program service centers right now we have approximately 2 million claims from the American public that we have not processed yet.

In our office of central operations, we have more than 1 million claims. Our office of hearings and appeals also has 1 million claims pending. Many of those claims, approximately 10 percent, are more than three months old and there is a number of them that are more than a year old.

We believe that the agency, feeling the pressure of trying to push out those work loads, has an expedient not addressed the issues of the quality of the product as much as we would like to see the agency do. We understand the pressures that are on the agency to serve the public the best way that we can and we know that sometimes it is important to, well, it is always important to process cases timely but it is also just as important to process them correctly.

We think that the new technology offers us a lot of challenges and, we think, a lot of opportunities. But we also think that we must be mindful of the impact of fraud and systems abuse that the new technology could possibly expose us to.

Moving out technology to our field offices without properly determining whether there is a potential for fraud and for systems abuse will only cause us more problems and will have an impact on our Trust Funds.

We think the agency needs to come to grips with the way we do business in the 1990s. The agency has traditionally structured their service delivery operation by having approximately 1,300 field offices around the country and 38 tele-service centers. We refer to them, within Social Security, as the mom-and-pop stores of America.

Frankly, we believe that the Walmarts and the Home Depots that are opening up all over the country are probably the most efficient way to operate. We think the agency must come to grips with that. In the New York City area, for example, where I'm from, we have approximately 55 Social Security field offices serving the American public. When we look at other public agencies that provide service to the American public, the number of offices are significantly fewer.

We think that the Social Security Administration pays a very high price for having these offices. We think that the American public for the most part would prefer to do business with us by calling us, by interacting with us using either telephones or the Internet.

We do think that we should have a presence in each community but we do have a particular concern about the extent of that presence and we think it is costing the American taxpayers a significant amount of money.

We, as managers in the Social Security Administration, also have some particular concerns about the number of managers and some of the efforts that have come out of the National Performance Review in terms of reducing the number of managers to employees. In our program service centers, by 1999, we are going to have one manager for every 38 employees on the line. That will not give us much of an opportunity to do much in the way of performance management in terms of working with employees and trying to motivate employees to achieve the best that they possibly can.

We think that a lot of the reasons why we are doing this is being driven by some arbitrary goals by the National Performance Review. We think that there is some room for improvement in terms of some of our excess layers. And we do believe in efficient government and we believe in lean government. But we think that we should take a realistic view of how we serve the American public in terms of structuring our organizations and we do not believe that we should be totally driven by artificial numbers or specific goals that we have to achieve.

We are extremely cognizant of some of the stories that we have heard coming out of the Internal Revenue Service these days. And we have particular concerns as managers within the Social Security Administration about some of the pressures that are being brought to bear on some of our managers to achieve artificial or arbitrary goals and numerical standards.

We believe in----

Mr. Porter. I am sorry to interrupt, but we have to stick within our 5-minute time limit. So, if you could finish your thought up we would be happy to oblige you.

Mr. Lawrence. Okay. We do thank the committee for the opportunity to speak before it. This is the first time we have spoken. We have a full document which we have submitted and we would ask the committee to consider our concerns.

Thank you.

[The prepared statement of Jerry Lawrence follows:]

Mr. Porter. Thank you very much for your testimony, Mr. Lawrence.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

Thursday, February 5, 1998.

WITNESS

WILLIAM W. MILLAR, AMERICAN PUBLIC TRANSIT ASSOCIATION

Mr. Porter. William W. Millar, President, American Public Transit Association, testifying in behalf of the Association.

Mr. Millar.

Mr. Millar. Thank you, Mr. Chairman.

Good morning, Mr. Chairman, I am William W. Millar, and I am the President of the American Public Transit Association.

I have submitted a statement for the record, so with your permission, that will go in the record and I will not take your time to read it. I am here really today for two reasons.

First, this is the first time that the American Public Transit Association has ever testified before this committee so we wanted to introduce our association to you and the members of the committee. And, second, we have some suggestions for making the very limited funds that you have referred to repeatedly through the morning go a little bit further than they are able to do now by taking use of the services that our members have to offer.

Before I describe that, I also need to say to you that many of our members that are in the Chicago area, when they heard that I was coming to testify before you this morning asked that I convey their good wishes to you and particularly thank you for the strong support that you have given the starting of Metro's new commuter rail service up through the North Central area, the Northern suburbs. It apparently has been a great success. So, we do thank you very much in your other role for strong support for public transit.

The American Public Transit Association is the largest trade organization that represents both the providers of public transit, such as the Chicago Transit Authority, the Pace suburban bus system, those types of operations, but also the private sector companies that supply the industry, for example, Gen Fare in Elkrow Village, Illinois, is a member of ours. So, we have both public sector and private sector members.

About 90 percent of all the people who use public transit in America every day utilize services that are provided by our members, just to give you a little bit of background.

Now, Mr. Chairman, we believe that public transit has much to offer. We believe that we can assist the very, very fine agencies that utilize the funds that your committee makes available to them to serve the American public. We believe we can make these limited funds go a lot further if we all work together.

I want to share with you today four specific ideas of how that might happen and offer to continue to work with you and the members of the committee and others to pursue this.

First, over the years, we have learned that coordination of transportation services is very important and that if the coordination is done right, we believe that it can really help the money go much further.

We are very appreciative that this committee, I believe, in the 1997 appropriations bill directed that some joint coordination guidelines be developed between the Department of Transportation and the Department of Health and Human Services. However, so far as we know, there has been no significant progress made on those guidelines since they were directed to develop them and we think they could be extremely valuable.

Despite not having the guidelines, there are numerous examples from around the country of where coordination has worked and worked well and, unfortunately, some examples where it has not gone so well. Let me give you two examples.

In Dade County, Florida, the Department of Social Services there has teamed up with the Metro Dade Transit Organization in Dade County to buy bus passes for Medicare recipients, medical assistance recipients. And in doing this and by using the services that are already on the street of the public transit agency, I understand they have been able to save over \$16,000,000 that was formerly going into medical assistance transportation.

On the other hand, not that far away in a nearby State, in Georgia, there the director of medical assistance without proper coordination, without discussing it with the local transit agencies or social service agencies merely issued an edict that cut the funding for medical assistance transportation in half. That may have looked very good in his budget but, unfortunately, it meant that many people were left without service and the Metropolitan Atlanta Rapid Transit Authority suddenly was faced with a \$6,700,000 rise in its budget and no funding to make up that shortfall.

Again, we think many of these problems could have been solved by proper coordination, by proper sitting down and talking and working things out. We think tens of millions of dollars still could have been saved in Georgia with a lot less heartache.

Another area that I want to turn to now is the whole issue of welfare-to-work. Certainly that has been one of the major discussions in this Congress and the previous Congress and Secretary Rodney Slater of the U.S. Department of Transportation has often said, public transit is the ``to'' in welfare-to-work. Well, we agree with him. We believe we can do that. We believe that again by coordinating with the agencies that have to find the jobs and get people to those jobs, transit can be a big help.

We were pleased recently that the Department of Labor issued some regulations on the distribution of funds for this effort and they did make transportation an eligible expense but they do not allow public transit agencies to apply for those funds. So, we would encourage the committee to allow that to happen.

Third, we believe that there are opportunities through

having as flexible as possible interpretations in HHS regulations to take advantage of the ADA, Americans With Disabilities Act, paratransit systems that our members are already implementing. And, so, we would encourage the committee to encourage the flexible interpretation of those regulations.

I guess my time must be up. Let me get my fourth point in if I can and then I will leave you. That is that we understand that studies have shown that HHS has over \$2,000,000,000 of its appropriations go to transportation purposes. Just on the other side of this wall there is a committee on transportation appropriation that deals with a lot of planning issues to make sure that transportation money is properly spent.

And yet, the HHS money is not involved in that planning process, the social agencies that distribute that \$2,000,000,000 do not sit at the table with the transportation planning agencies to see that there is proper coordination and proper connection. So, our final point would be that we would ask that you encourage both the Department of Health and Human Services, as well as the Department of Transportation to bring those social service agencies to the table to have them participate in the regional planning processes so that together we can work out the best possible coordinated services for the public.

We thank you very much for the opportunity to be with you, sir.

[The prepared statement of William Millar follows:]

[Pages 1911 - 1920--The official Committee record contains additional material here.]

Mr. Porter. Mr. Millar, I think you have made a lot of very valid points. And we are delighted that the Public Transit Association can be here for its first time but let us make it continuous in the future. Because I think you are exactly right, there are a lot of savings that can be achieved through better coordination. I will follow-up with the HHS and the Department of Transportation to see why that has not proceeded more quickly. And, obviously, we want to do exactly what you said, we want to save as many resources as we possibly can and you are, obviously, willing to help us do that, so, we are anxious to work with you.

Thank you so much for testifying.

Mr. Millar. Thank you very much.

Thursday, February 5, 1998.

WITNESS

DAVID R. BICKERS, M.D., THE SOCIETY FOR INVESTIGATIVE DERMATOLOGY

Mr. Porter. David R. Bickers, M.D., Secretary-Treasurer, Society for Investigative Dermatology, testifying in behalf of the Society.

Dr. Bickers. Mr. Chairman, thank you very much.

I am David Bickers. I am a dermatologist. I represent the

Society for Investigative Dermatology. We have some 2,000 members nationwide, scientists, researchers and university hospitals, industry across the United States.

We are engaged in research to discover ways to improve the quality of life of the American people who suffer from diseases of the skin which number in excess of 60 million individuals.

We do support the Ad Hoc Group for Medical Research Funding calling for a 15 percent increase in Fiscal Year 1999, as a first step toward doubling the NIH budget over the next 5 years.

Mr. Chairman, I have also brought with me today a booklet that has been made available, I think, to members of the committee that from which most of my testimony will be derived and additional copies are available if anyone is interested.

Basically diseases of the skin produce devastation not only because of the damage they do to the tissue, itself, but also to the individual's self image. For example, young people with severe acne who have resultant scarring may have, and studies have shown, difficulty finding employment as compared to individuals not so affected.

Similarly, people who have early premature loss of hair, like you and me, are sometimes looked upon as prematurely old. And be that as it may, what I would like to focus on for a minute or so are some recent advances that highlight the potential that exists and also to express gratitude to the Congress for the support that led to these discoveries.

For example, there has recently been discovery of isolation of genes that are responsible for skin cancer, the most common form of human cancer. With these insights I think it is reasonable to predict that we will have better strategies for preventing skin cancer in the not too distant future.

A second very exciting and very recent discovery just published last week in Science that, in fact, the discovery of a member of my own Department in Columbia, relates to the first human mutation for hair loss. And this is actually an interesting story of research and international good will. The investigator, Dr. Angela, Christiano, herself about two years ago, suddenly noticed that she was losing large clumps of hair from her scalp. She went into the medical literature to ascertain what was known about the condition, in this case, Alopecia areata, and was appalled to find how little science there was to explain the disorder.

She, at the same time, found reference to a family or several families in Pakistan who had several generations in whom individuals were born with hair but subsequently lost all of their body hair. She contacted a doctor in Islamabad and that led then to a trek into the wilderness of Pakistan in which samples were obtained from these family members. Brought them to New York and then Dr. Christiano then set about to find this gene.

I am happy to say that in the paper published in Science last Friday based on the studies done in this family she was able to show for the first time a human gene mutation for hair loss.

While on one level one could say, well, this is a cosmetic problem. But, point of fact, this discovery could lead to profoundly important insights into regulation of hair growth,

and since many skin cells originate in hair, it could also lead to discoveries that could help us with technologies to, for example, find better ways to provide skin replacement for patients with burns, et cetera.

The other point about this research is interestingly we hear criticism and concerns about the experiments in animals, the final link in the chain finding this gene for hair loss came about because of a mouse model in which the hair falls out and that gene had been discovered and it helped the doctor to find this gene on chromosome 8.

Finally, let me say that we have, our society has worked in close collaboration with the Coalition of Patient Advocates for Skin Diseases Research and these individuals have been a powerful voice for those who suffer from the ravages of skin disease and together we have put together this document that highlights not only the achievements but the opportunities that are before us.

Finally, I would like to thank you, Mr. Chairman, for your strong and sustained advocacy for bio-medical research. I think we are on the brink of discoveries that could profoundly improve the health of the American people and our society is committed to waging that war with your generous support.

Thank you very much.

[The prepared statement of David Bickers, M.D., follows:]

[Pages 1923 - 1929--The official Committee record contains additional material here.]

Mr. Porter. Perfect timing, Dr. Bickers.

Let me thank you for your testimony. I appreciate that you said my hair loss was premature, I doubt that; I think it is probably mature rather than premature.

We had someone in yesterday to testify from the Alopecia Areata Foundation I think it was, and obviously the discovery of this gene is extremely exciting and the subjects that you raised for us, I think, are important ones. We are going to do the best that we can to provide the resources that are needed.

Thank you very much and thank you for your testimony this afternoon.

Dr. Bickers. Thank you very much.

Mr. Porter. Thank you, Dr. Bickers.

Thursday, February 5, 1998.

WITNESS

ANTHONY COLE, HAYMARKET HOUSE

Mr. Porter. I am going to have to leave to make a speech off of Capitol Hill and I am going to ask Mr. Wicker of Mississippi to take the chair in just a moment.

But first I want to introduce our next witness, Anthony Cole, the Vice President of Haymarket House, testifying in behalf of Haymarket House, and Mr. Cole, it is great to see you again. I have been down to Haymarket House in Chicago to see

the really very effective operation that they run in behalf of people at-risk in a number of different ways. And I am sorry that I cannot stay to hear your testimony. Mr. Wicker is going to take the chair, but Mr. Cole it is really wonderful to see you here and we thank you for coming to testify.

Mr. Cole. Thank you very much, Chairman Porter. And our founder sends his best regards.

Good afternoon.

I want to thank Mr. Wicker and the other members of the committee for providing Haymarket Center with the opportunity to present testimony to your subcommittee again this year.

My name is Anthony Cole and I am Vice President of Haymarket. We are a comprehensive substance abuse treatment center on the near West side of Chicago. Over the past 23 years, we have developed several unique programs to address the needs of high-risk females and non-violent drug offenders.

I present this testimony this year to provide a status report on Haymarket's ongoing efforts to be innovative and effective in our programming. We, at Haymarket believe that the treatment community needs to be encouraged to fully develop and refine what is called a continuum of care. This continuum is the integration of drug abuse prevention, drug abuse treatment, health services, including HIV-AIDS, day care, parent training, vocational education, job placement and screening for domestic violence and gambling addiction.

We also believe that the treatment community needs to equip ourselves with a better understanding of which treatments are most effective for which subgroup of users. We need to recognize that program models developed to treat a white, male population are not directly transferrable to other groups like pregnant and postpartum women. These clients bring with them a whole other set of clients--their children.

Haymarket believes that the Federal Government's limited prevention and treatment resources need to be targeted toward high-risk and hard to place populations such as women and their children, especially when one considers that the greatest cost savings associated with treating this population.

In addition to the savings connected to treating the mother, there are significant savings to be realized by delivering drug-free infants. The expense of intensive hospital care for each drug-exposed newborn ranges from \$20,000 to \$40,000. The average total cost of care from birth to age 18 for each drug-exposed child is \$750,000 according to the General Accounting Office.

I also recognize that this subcommittee receives no credit or benefit from savings to the Medicaid program resulting from an increased appropriation for treatment. This is unfortunate. Just look at the numbers. At least one in every five Medicaid dollars spent on hospital care is as a result of substance abuse, at a cost of \$8,000,000,000 a year.

Haymarket remains concerned that as this trend of shifting public health care to managed care continues, little attention is being paid to how to effectively transfer managed care practices to publicly funded residential treatment settings without negatively impacting treatment outcomes.

We are asking that this committee, that we all know that the research shows that the longer length of residential stays

are highly correlated with successful treatment outcomes. Haymarket believes that there is a direct correlation between the comprehensive nature of treatment and reductions in the recidivism rates.

Accordingly, we have incorporated a preventive health services clinic into our treatment programs. Through the establishment of an on-site clinic in partnership with a highly qualified community health center in Chicago, we have been able to address a variety of medical and health problems which impede our clients' treatment progress.

We urge the committee to encourage the CDC and HRSA to continue to work with community-based organizations to control the spread of infectious disease, the reduction of chronic diseases and the reduction of risk factors through preventive and primary health care.

Finally, Haymarket is looking to expand vocational education and job placement services we offer our clients. Once we have completed treatment and have begun to address their other medical and health-related problems the one impediment is a lack of employment opportunities. Haymarket is looking to collaborate with the Job Corps center which is scheduled to open in Chicago this year in developing an outpatient demonstration project. We ask that the committee encourage the Department of Labor to consider working with community-based organizations in this and other innovative ways.

Clearly, if welfare-to-work efforts are going to succeed, demand for substance abuse treatment will increase and exceed the capacity of the current system. For example, the Illinois Department of Health and Human Services estimates that 40 percent of our TANF population has a substance abuse problem and is in need of treatment. Thus, for welfare-to-work to succeed, it must include substance abuse treatment funding increases.

In closing, Haymarket requests that you help the treatment community create a continuum of care for individuals with drug abuse problems so those individuals can address their problems more quickly and completely.

Thank you very much.

[The prepared statement of Anthony Cole follows:]

[Pages 1933 - 1940--The official Committee record contains additional material here.]

Mr. Wicker. Thank you, Mr. Cole, we appreciate your testimony.

Thursday, February 5, 1998.

WITNESS

KAREN JOHNSON, FSH SOCIETY, INC.

Mr. Wicker. Our next witness is Karen Johnson, Board Member of the FSH Society, speaking to us today. We are delighted to have you with us today.

Ms. Johnson. Thank you, Mr. Wicker. Thank you for letting me submit this testimony to you today. As stated, my name is Karen Johnson and I am from Bowie, Maryland, and I am testifying as a Member of the Board of Directors of the Facioscapulohumeral Society, the facilitator for the Mid-Atlantic FSH support group and as an individual who has this disorder.

FSH disorder, otherwise known as Facioscapulohumeral, muscular dystrophy or FSHD, is an inherited neuromuscular disorder affecting one in 20,000 people. FSHD causes a progressive and severe loss of skeletal muscle throughout the whole body. As an American with FSHD and generations of my family afflicted with FSHD, I would like to tell Congress just how hard it is for a family to deal with this disease.

FSHD has diminished me physically. There is no cure or treatment. I live with physical and emotional pain and the frustration of losing independence daily. Both of my brothers have FSHD. I watch them endure it for a lifetime.

My only child has FSHD. I wish that he not see his mother progressively weaken knowing that he is watching what is certain to be his fate. Surely he knows at his age that without a cure he, too, will progressively weaken and be burdened with a diseased body.

It is physically impossible for me to hug my son. I cannot tell him any more that it will be all right. I watch helplessly as his carefree personality changes into that of a depressed young man burdened with the realization that he has inherited his disease from me. I worry about the day that he brings home his forever love with the fear that she will not be strong enough in seeing what he will become.

I worry for the happiness in future of my grandchildren because FSHD is inherited. My husband will soon be my caregiver for I cannot walk. I cannot roll over or get out of bed. I cannot close my eyes to sleep and feeding myself is getting more difficult.

I need assistance with bathing, toileting and dressing. And all the while my son sees my pain, my anguish, and my increasing disability and I see his fear. How can a mother reassure their child if she, too, is unsure?

Largely, thanks to the efforts of Mr. Porter, the National Institutes of Health Researching Fund continues to grow. This past year has seen an unprecedented level of communication between the research community, the FSH Society, NIH and Congress. We are indebted to the members of this subcommittee and Representative Edward J. Markey from Massachusetts for his support. And for the report language submitted to you last year co-signed by Representatives McHugh, Frank, Meehan, Schumer, and Wexler.

While we wait for a formal response to last year's report language from Congress to the Director of NIH, we need Congress to give NIH resources now for FSHD research.

Understanding that the process takes time, we are positive we will see major initiatives in this area. Today, I am asking Congress to communicate to the NIH its awareness of our current crisis on research with FSHD.

Mr. Chairman, there is perhaps \$200,000 of funding on FSHD from NIH and this is clearly insufficient. Congress must act on

the one item that we cannot do for ourselves, that is to fund research on FSHD. We need a commitment to the FSHD research in areas outlined by the international community of scientists working on FSHD.

We ask the subcommittee to assign a dollar amount to FSHD research. We request that an amount of not less than \$2,000,000 and not more than \$4,000,000 be earmarked for FSHD research.

The men, women and children who live with this devastating disease are taxpayers and contributors to the American way of life. With an 88 percent employment rate we personally bear our burden of health care costs and training expenses to maintain financial and personal independence.

We implore that the United States Government allocate our hard-earned tax dollars commensurate with our numbers and valuable contributions to the American way of life and society. Time is of the essence now. Lives are in the balance. The FSHD community demands bold, persistent and innovative initiatives.

We ask you to, please, act today for our children, my child, and the generations to come. I have brought along a statement from the FSH Society to be included in the record. And I really appreciate you looking that over.

Again, I want to thank you.

[The prepared statement of Karen Johnson follows:]

[Pages 1943 - 1953--The official Committee record contains additional material here.]

Mr. Wicker. Thank you, Ms. Johnson, for your very effective testimony. I am sure that if Chairman Porter were still here he would express to you that he intends to do his best as chairman of this subcommittee to work with the scientists and physicians at NIH to see that these scarce public resources that we have are used most effectively.

And I certainly hope that we can bring some relief to you.

Ms. Johnson. Thank you.

Mr. Wicker. Thank you very, very much.

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Thursday, February 5, 1998.

WITNESS

KAREN HENDRICKS, COALITION FOR HEALTH CARE FUNDING

Mr. Wicker. Our next witness is Karen M. Hendricks, President, Coalition For Health Funding and Assistant Director, Department of Government Liaison, American Academy of Pediatrics.

Ms. Hendricks, we are delighted to have you with us.

Ms. Hendricks. Thank you, Mr. Wicker.

The Coalition for Health Care Funding is very pleased to have an opportunity to present our statement recommending Fiscal Year 1999 funding levels for the agencies and the programs of the Public Health Service. We sincerely appreciate the strong and continued support that this subcommittee has

given to help discretionary programs.

This year we celebrate the Bicentennial of the U.S. Public Health Service. For 200 years, the Public Health Service has been protecting the health of the American public beginning with the establishment of the Marine Hospital Service to care for sick and disabled Navy men in 1798.

While we have seen major advances in medical care over the past 200 years, the greatest impact on people's lives and well-being has been in the arena of public health. Since the turn of the 20th Century life expectancy of Americans has increased from 45 to 75 years. A recent report estimates that five of those added years are due to the medical care system but 25 years are due to the public health interventions.

Dr. William Foege, a former Director of the Centers for Disease Control and now with the Carter Center in Atlanta, noted in a recent PBS Television documentary recounting the progress of medicine, ``One of the most remarkable things of this century of science has not been what happens in the emergency room or in an intensive care unit or in the laboratory, it is the information now available to the average person about how to live longer and stay healthier.''

Disseminating this information to all Americans is largely the work of public health agencies like the CDC and HRSA. The Coalition appreciates that many members of this subcommittee will want to provide a significant increase in the funding for NIH in the coming Fiscal Year. The Coalition agrees.

However, as we both know, other sources of funding beyond the amount available under the current tightly capped discretionary accounts will need to be found to support the NIH and all other Public Health Service agencies. The Coalition has in the past and remains committed to working with the budget committees and others to increase funding for NIH in a manner that does not rob Peter to pay Paul.

Biomedical and behavioral research provides the foundation that underlines a continuum of public health activities that include health services and outcomes research, targeted health care delivery to special populations, health professions education and training, disease and injury prevention and control, and health promotions activities.

Without these essential public health partners our increasing investment in biomedical research will fail to achieve the goal of a healthier and more productive nation. Recently the Coalition was approached for examples of how our investment in NIH-sponsored research eventually translates into healthier lives for our citizens through the actions of other agencies of the Public Health Service. Let me give you just one or two examples.

We have relied on NIH-sponsored research to identify the mysterious and tragic causes of SIDS, deaths in young infants but have looked to the Maternal and Child Health Block Grant program to deliver and implement the back to sleep campaign that has reduced SIDS by approximately 38 percent.

In the area of chronic disease, our investment in NIH research has identified a limited number of unhealthy lifestyle behaviors, many adopted early in life, which contribute to billions of dollars in direct and indirect costs due to heart disease, cancers, diabetes, and intentional and unintentional

injuries. Investing in nationwide disease prevention and health promotion activities to reduce this largely preventable national burden would more than pay its way.

As we stand on the brink of the next millennium, our continued investment in a very strong Public Health Service will help us address these ongoing challenges and help us deal effectively with the newest challenges.

The challenges of the next millennium include keeping our food and water supply safe, discovering effective methods for addressing new and emerging and multi-drug resistant infectious diseases, and identifying and protecting the work place, our homes and communities from chemicals that are harmful to health while we continue the effort to provide quality, cost-effective health care to all Americans.

For Fiscal Year 1999, the Coalition is recommending \$29,000,000 be provided to address the nation's needs in the areas of biomedical, behavioral, and health services research; disease prevention and health promotion; health services for vulnerable and medically under-served populations; health professions education and training; substance abuse and mental health services; and food, drug and medical device regulation. The members of the Coalition for Health Funding look forward to working with this subcommittee and meeting the difficult public health challenges that are still ahead.

Thank you.

[The prepared statement of Karen Hendricks follows:]

[Pages 1956 - 1964--The official Committee record contains additional material here.]

Mr. Wicker. And we look forward to working with you.

It is perfectly all right in this building to yield back some time. Remind us of that and you will get it back next year.

Thursday, February 5, 1998.

WITNESS

MICHAEL Q. FORD, NATIONAL NUTRITIONAL FOODS ASSOCIATION

Mr. Wicker. Our next witness, Mr. Michael Q. Ford, Executive Director, National Nutritional Foods Association.

Mr. Ford, we are delighted to have you with us.

Mr. Ford. Thank you, Mr. Wicker.

It is an honor to be here and I want to thank the staff, too, for their flexibility in changing around the schedule so that I could be here today. The National Nutritional Foods Association represents about 2,500 health food stores and about 800 manufacturers, distributors and suppliers of health foods, dietary supplements and natural ingredients, cosmetics, and we want to talk to you today about increased research on the benefits of dietary supplements, particularly nutrient vitamins and herbs and other botanicals.

In yesterday's, sometimes it works out very well, in

yesterday's Washington Post this article appeared on page A-3. The headline says, ``Vitamins Sharply Reduced Risk of Heart Attack Study Finds.''

This was a very large study, 14 years, 80 thousand nurses, Harvard School of Public Health, published in the Journal of the American Medical Association. And what it says is two simple B vitamins, Folic Acid and B-6, taken in amounts regularly larger than what is recommended by the FDA as the recommended daily allowance, can reduce the risk of heart attack by 50 percent. I mean this to us is just a wonderful revelation and I think for all Americans it is a wonderful revelation.

We have more than 100 million citizens of this country taking dietary supplements, herbs and vitamins, every day and the Congress has mandated more research and more service in this area, particularly with the passage of the Dietary Supplement Health and Education Act of 1994.

Two scholarly documents have recently been published that support more research in this area. One is by the Food and Nutrition Board of the National Academy of Sciences which is the body responsible for creation of the RDAs. They now, for the first time, since the RDAs were created in 1941, are talking about optimal health and using nutrients to fight chronic disease other than the classical nutrient-deficiency diseases, like beriberi and scurvy. And the chairman of the Food and Nutrition Board calls this particular report a great leap forward and we agree with him.

Also the President's Commission on Dietary Supplement Labels, which was created by the Dietary Supplement Act, has come out very strongly in support of increased research in this area saying the public interest would be served by such research.

We are looking for a continuum of research in this area that goes like this. There is at the NIH the Office of Dietary Supplements, again created by the Dietary Supplement Act, which is to coordinate and stimulate research on dietary supplements, other nutrients and the botanicals. This office is currently funded at about \$1,000,000 with 1.5 FTEs. We support the President's Commission in calling for the full authorized funding of this office at \$5,000,000, so that they continue to stimulate the kinds of research that will give us the results as reported in the Washington Post.

Secondly, the Office of Complementary and Alternative Medicine, created in 1992 by Congress as the Office of Alternative Medicine, is currently funded at about \$20,000,000 which is very good, but it does not come close to mirroring the popularity and importance of alternative providers. The New England Journal of Medicine has said that in an average year 425 million visits are made to alternative providers as compared to 338 million visits to contemporary, to traditional doctors and primary care givers.

We would like to see the funding for research in this area mirror the national demand for these kinds of services which often use nutrients and botanicals and herbs.

Also, we do support Congressman D'Fazio's H.R. 1055, which would elevate the Office of Complementary and Alternative Medicine to a center status so that it could make its own

agenda, have its own peer review panels and let its own grants and contracts.

Once we have the kind of research that is necessary from NIH, we would like to see the subcommittee consider directing the agency for health care prevention and research to look at the feasibility of cost effectiveness studies of some of the products that are bringing such relief to people with chronic illnesses and doing a great job of preventing. For example, Saw Palmetto is a botanical which is shown to be much more effective with no side effects with respect to treating benign prostate enlargement. We think that there would be cost effectiveness and the AHCPR would find this because people will take their medicines when there are not the kind of side effects that come so often with prescription drugs.

We would hope with the cost effectiveness shown the committee would eventually consider some sort of demonstration project through Medicare and Medicaid and the Health Care Financing Administration.

Thank you for your time and I would ask that in addition to our formal statement, we have submitted a copy of this article from the Washington Post about the Harvard study and I would like that to be made a part of the record.

[The prepared statement of Michael Ford follows:]

[Pages 1967 - 1975--The official Committee record contains additional material here.]

Mr. Wicker. Thank you. That will be received.

[The article from the Washington Post follows:]

[Pages 1977 - 1979--The official Committee record contains additional material here.]

Thursday, February 5, 1998.

WITNESS

JUDITH S. STERN, Sc.D., AMERICAN OBESITY ASSOCIATION

Mr. Wicker. We will now hear Judith Stern, Dr. Judith Stern, Vice President, American Obesity Association.

And at the end of Dr. Stern's testimony I may have to make a mad dash on the floor to vote.

Dr. Hadley, who is our final witness will testify at 2 o'clock and at the conclusion of Dr. Stern's testimony we will stand in recess until 2 o'clock.

Dr. Stern. Thanks, Mr. Wicker.

I am reporting the American Obesity Association and it was founded in 1995 to serve as an advocate for millions of persons in this country suffering from obesity. I am also a professor of nutrition and internal medicine at the University of California, Davis, and I have served as Presidents of the American Society for Clinical Nutrition and the North American Association for the Study of Obesity and I am a member of the

Institute of Medicine, National Academy of Sciences.

Today, I have come to talk with you very briefly about the growing epidemic of obesity in America where obesity affects a minimum of 58 million adults and 5 million children. And if this were tuberculosis nobody would doubt that it was an epidemic. Former Surgeon General Dr. C. Everett Koop has taken up this banner and he has pointed out that obesity is prematurely killing 300,000 Americans each year, and Dr. Koop knows that I am here this morning and supports my testimony.

Obesity is second only to smoking as the leading cause of preventable death but obesity does not appear on the 300,000 death certificates. People are dying of diseases casually linked to obesity like heart disease and hypertension and stroke and Type 2 diabetes and certain cancers and these are the diseases that appear on death certificates.

Putting this in perspective this is the equivalent of four Oklahoma City bombings a day for a year. It is a lot.

Why do people die of obesity? There is no longer any doubt that obesity interferes with a number of physiological functions and metabolic processes. Cardiovascular, respiratory, they are all negatively impacted.

The utilization of nutrients, especially glucose, is abnormal and the result is hypertension, and dyslipidemia, and atherosclerosis and eventually heart disease and diabetes.

Obesity increases the risk for all of these diseases. Once they are established weight gain makes it worse, and a little bit of weight loss improves it but what I am really here for today is to really object to the fact that the NIH is devoting far too few resources to obesity research especially in relationship to the number of premature deaths and the costs of obesity are staggering.

The best figures we have are from 1986 and more than \$67,000,000,000 a year and including \$22,200,000,000 for the cost of obesity related to heart disease; \$11,300,000,000 per year spent to treat and manage Type 2 diabetes, nearly all of whom are obese; \$2,400,000,000 for gallbladder disease associated with obesity; \$1,500,000,000 for the treatment of high blood pressure and it goes on.

Now, Mr. Wicker, the NIH only spends \$92,000,000 a year for obesity research. You work it out. That is a \$1.46 per obese person. Compare that \$1.46 to \$20 per diabetic person, \$40 on each patient with heart disease; \$338 for cancer; and \$2,101 for each patient with HIV-AIDS.

So, I think the Department of Health and Human Services needs a complete reevaluation of its response to this obesity crisis and NIH must have a budget that appropriately reflects the prevalence, health consequences, and costs of obesity. Funding is vitally needed for basic and clinical research in obesity, prevention and intervention research. So, in conclusion, on behalf of the 63 million obese Americans, who are living and dying prematurely with this disease, we urge this committee to make a five-fold increase in the money that NIH spends on obesity research. It would only raise it from the current \$92,000,000 to \$460,000,000 in Fiscal Year 1999.

Mr. Wicker, I really thank you for your time and attention and I would like to urge you to recall that one of three out of your constituents is struggling with this disease. It is an

awful.

[The prepared statement of Judith Stern follows:]

[Pages 1982 - 1988--The official Committee record contains additional material here.]

Mr. Wicker. Dr. Stern, if a person can get through childhood and adolescence without having obesity, are their chances of becoming obese as an adult reduced dramatically?

Dr. Stern. Somewhat, but 53 million of the 58 million obese adults became obese as adults. There are only about 5 million obese children and I think it is, Mr. Wicker, genetics is important, that sort of loads the gun, but environment pulls the trigger. There is a problem with inactivity and food intake but there is that underlying genetics. And we can make great progress, we need the money.

Mr. Wicker. I hope we can be of service.

Thank you very much for your testimony and this subcommittee stands in recess until 2 p.m.

Dr. Stern. Thank you.

Thursday, April 30, 1998.

TESTIMONY OF MEMBERS OF CONGRESS

WITNESS

HON. FRANK PALLONE, JR., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY

Mr. Porter. The subcommittee will come to order. We continue our hearing on the appropriations for fiscal year 1999, and we will hear this morning and this afternoon from Members of Congress, and we are pleased to welcome our colleague, Frank Pallone of New Jersey. We will allocate 5 minutes to each of our witnesses.

Frank, please proceed.

Mr. Pallone. Thank you, Mr. Chairman and members of the committee. Hopefully I won't use the 5 minutes. I will submit my statement for the record and just highlight four areas of concern.

One is impact aid. I have a number of towns in my district that received impact aid because of the soldiers or sailors that are stationed there, and I am just requesting that the subcommittee provide the level of funding that has been recommended by the Impact Aid Coalition, which I understand is 887 million for the fiscal year, as opposed to I guess 609 million that the President has requested. I know that your subcommittee usually does better than what the President requests on that, and I would just hope that you do that once again.

The second issue is what we call RUNet 2000, which will be based at Rutgers University, which is the State university in my district. RUNet 2000 is basically a comprehensive, integrated, voice video data and communications network.

Rutgers, although the major campus is in my district, it also has campuses in Newark and Camden, New Jersey. And

basically this is a way of sort of linking not only the three campuses at Rutgers, but also with other institutions of higher education. It is essentially a creative approach to share research expertise and instructional talents with people far beyond the university.

Very quickly, this is a 5-year plan. To put this together, it will cost \$100 million. We are looking for 10 percent of the funding or \$10 million from the Federal Government, strictly for capital costs, not for actual operations of this network. It is something innovative; I would like the subcommittee to look at it and consider it.

The third thing I wanted to mention is the Job Corps. I know you have been very supportive of the Job Corps program and I just wanted to say that it works very well in my district. I get a lot of information from the Edison Center, which has been very successful in terms of the opportunities for the individuals that have been involved.

Just to give you an idea, 75 percent of the students in this program went on to join the work force, the Armed Forces, or to continue their education. It has just been a very successful program in terms of people's futures, as well as the hands-on activity they are involved with, and I would just ask that you continue to support the program by providing \$1.3 billion for the next fiscal year.

The last thing I wanted to mention is harmful algal blooms. They call them HABs, another acronym. This has plagued humans for a long time. But the biggest problem now--you remember in Chesapeake where we had the *Pfisteria* blooms and in the Gulf of Mexico we had the red tide. In both cases, there have been a lot of chronic illnesses that have resulted from exposure to these harmful algal blooms, and they are known to be responsible for about five different types of seafood poisoning.

What I am asking for is more money to do research on the consequences of these harmful algal blooms. The National Institute of Environmental Health Sciences--I am sorry, the National Institute of Environmental Health Sciences is, of course, part of the NIH and they are the institute that has the mandated permission to address these harmful algal bloom issues. Basically there is not a lot of research on it right now, because these environmental problems from the algal blooms are increasing. I am asking that you put a \$10 million increase into this institute, specifically to address the effects of these harmful algal blooms on humans.

There are a lot more studies that need to be noted and, of course, you have seen in the papers these have received a lot of attention lately, and I am concerned it is a growing problem that needs more attention at the National Institute.

That is all I wanted to address and I appreciate all your efforts in the past, certainly.

[The prepared statement of Congressman Frank Pallone, Jr., follows:]

Mr. Porter. Frank, thank you for your testimony. Obviously we have agreed with you on Impact Aid and Job Corps being high priorities. Depending on our allocation, we will hope to agree with you again and certainly look into the RUNet 2000 and--it is HAB; right?

Mr. Pallone. Right.

Mr. Porter. With which I was not familiar.

Mr. Pallone. I was not going to use the acronym because it is not familiar to me either.

Mr. Porter. We will do our best to respond in both those cases.

Mr. Pallone. Thank you.

Mr. Porter. Thank you, Frank.

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Thursday, April 30, 1998.

WITNESS

HON. BILL GOODLING, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF PENNSYLVANIA

Mr. Porter. Next we are pleased to welcome the Chairman of the authorizing committee, Education and the Workforce, Congressman Bill Goodling of Pennsylvania.

Bill, it is good to see you.

Mr. Goodling. Thank you, Mr. Chairman. I will take my 5 minutes.

Mr. Porter. Very good.

Mr. Goodling. First, I want to thank you for having the opportunity to testify. I would like to first focus on IDEA and first, by thanking you and your committee for your efforts in the last couple of years. The more than 1.4 billion funding increases you have given since we have been in the Majority certainly is very, very helpful not only to the children, but also to the local school districts. As you know, when it was passed in 1975, we said we would send 40 percent of the excess costs, since we sent 100 percent of the mandates; and thank goodness, at least in the last 2 years, we are now up to 9 percent, a long way from 40 percent, but we are getting there.

If we have another 1.1 billion in IDEA part B, we trigger in a new formula and that will get us away, hopefully, from identification of students. The new formula also will be able to help local school districts because it will be the first time they will be able to reduce their spending. Not the States. They have to continue with the local district, and so they will be able to do all those wonderful things the President talked about in the State of the Union that are none of our business in the first place. But they can do pupil-teacher ratios, improve school buildings, and new buildings and so on, if we send them what we promised we would send them when we sent the mandate.

A good example is the city of York, which is a small city. They spent about 16 percent of their entire budget on our mandate from the Federal level. We sent them about 7.5 percent of the money. If we sent the extra money that we promised,

there would probably be another million dollars, and they could do all sorts of things to improve teacher training, they could do all sorts of things to reduce pupil-teacher ratio, all the things the President talked about.

Mr. Porter. Did you say that if we add \$1.1 billion----

Mr. Goodling. No; if we ever got to the 40 percent.

Mr. Porter. Oh, if we got to the 40 percent.

Mr. Goodling. The 1.1 billion will at least help them to reduce their spending on special ed so they can do some other things for all the rest of the students that they have. So it would be very helpful if we can continue what you started 2 years ago toward that promise.

The second issue I would like to talk about is I hope we have put testing to bed until the authorizing committee authorizes. We had a big vote again in the House. The Senate also voted, I believe, 52 to 47 to follow our lead. So I would hope now it would be a joint effort on the House and the Senate side to make sure we don't move ahead without authorization on any field testing and any pilot testing, anything.

Mr. Porter. You are saying we will need a provision in the bill this year to continue what we started, what you started last year.

Mr. Goodling. We will----

Mr. Porter. On testing.

Mr. Goodling. Right. You will need to make it very clear that you are abiding by the will of the House and the will of the Senate in relationship to funding for testing.

Let me then go on to something very near and dear to me, which is Even Start. We finally found a family literacy program that works, after all these years, and I have given you copies of the evaluation; a very outstanding evaluation. Now instead of saying what they said about Head Start so many years when we didn't have quality in the program--they would always say there is no Head Start by the time they get to third grade. This evaluation indicates from all the teachers and administrators that what they have gained in Even Start is a continuation beyond third grade, that they really hold onto what they gain, and we make the parents better parents and improve their literacy so they can be the child's first and most important teacher.

So instead of the \$9 million cut--which I assume was sending a message to me--in the President's budget, I would recommend a \$9 million increase, because we finally found something that works. It is amazing because last year he asked for an increase, because he told the Secretary that he really liked the program in Ireland where they had the parents over here working with them and the preschool children over here and they bring them together. And, of course, I said, Mr. Secretary, they stole that from us, you know. We have been doing it for 10 years and it has been very effective.

The next area I would like to mention is Chapter 2; it is now Title VI. I see he zeros that out. But, again, it is that block grant that really gives the local school district an opportunity to improve their teaching, and so I would hope that we would not pay attention to his budget.

I would also like to point out migrant education. When you talk about disadvantaged, these are the most disadvantaged of

all, nobody looking out for them. They haven't gotten any increase in the last 2 years. Of course, they have a tremendous increase in numbers, but no increase as far as money is concerned. So I would hope that we can take a look at that.

Since I don't have time to get into the work force issues, I would merely say that I would refer you to my written testimony for fuller explanation.

I just simply want to emphasize the Department of Labor funds should focus on helping employers, employees, and unions voluntarily comply with and better understand workplace laws. That is the drive we have on, we have gotten them away from this business of the more fines they get, the better they can run their department, so those are the areas that I want to highlight.

[The prepared statement of Congressman William F. Goodling follows:]

[Pages 2000 - 2008--The official Committee record contains additional material here.]

Mr. Porter. Bill, thank you. I think that we can, depending on our allocation, we can be responsive in each of these areas, and we certainly agree with you on IDEA and how it frees up funds at the local level to do things that otherwise couldn't be done. And certainly testing, Even Start, Title VI, all these are things that we very much agree with you on.

Mr. Goodling. Just one other statement. At 11 o'clock last night, I reminded them on the floor they are their making each other feel good with some of these programs that they are now accepting in our higher ed bill. I would just encourage you not to pay any attention to those whatsoever, because I reminded them that if you would appropriate, then they are going to come from some other place and it just might be one of their favorite programs where they had to take money in order to ignore these amendments for a couple of them that were accepted because they don't merit your recognition. Thank you.

Mr. Porter. All right. Thank you.

Thursday, April 30, 1998.

WITNESS

HON. BUCK McKEON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mr. Porter. Next we are pleased to welcome our colleague from California, a member of the authorizing committee, representative Buck McKeon. Buck, good to see you.

Did he say something he shouldn't have said?

Mr. McKeon. No; we were just kidding about that.

Mr. Chairman, thank you for the opportunity to speak before your subcommittee this morning. I am pleased to testify this morning with my colleagues on the Committee on Education and the Workforce on the fiscal year 1999 funding priorities for postsecondary education and adult training programs.

As you are aware, the Higher Education Amendments of 1998 are currently being considered on the House floor. This bill was adopted by the full committee with strong bipartisan support, passed out of committee 38 to 3.

It brings us closer to my goal of ensuring that every American who wants a quality education at an affordable price will be able to get it.

I would like to take the opportunity today to briefly explain the changes we have made in this important piece of legislation.

The committee is proud of the accomplishments made to date in making college affordable for all students since the Republicans gained control of the Congress. For example, Pell grants and college work study are funded at all-time highs, while provisions in the Taxpayer Relief Act created education IRAs and other tax credits to help low- and middle-income students obtain a postsecondary education.

The Higher Education Amendments will build on these achievements by continuing the important programs that serve students well and by reforming burdensome requirements to best meet the needs of students, families and colleges across the country.

The Higher Education Amendments of 1998 will simplify the student aid system. Our legislation will eliminate 45 unfunded programs, including the State postsecondary review entities, and terminate 11 studies and commissions. It will bring our student financial aid delivery system into the next century by creating a performance-based organization within the Department of Education, focused on providing quality service to students and parents.

For the first time, the day-to-day management of our student aid programs will be in the hands of someone with real-world experience in financial services. This individual will be given the hiring and contracting flexibility necessary to get results and will be paid based on performance.

For the first time, the Department's student financial aid systems will be run like a business. This performance-based organization will manage the Department's computer systems and ensure that the Department of Education does not waste money due to poor contract management or duplication. I don't know why we have to do this. In law, it seems to me like that would have been something they would have already done but they didn't, so this will improve that system.

The bill also requires the Secretary to work with the higher education community to adopt common and open electronic data standards for important parts of the delivery system. By adopting these common standards, we can greatly simplify the student aid system by eliminating paper forms and unnecessary steps in the process. The student will fill out one piece of paper that will work for all their financial needs, instead of having to respond to many different forms.

Many other improvements we made in the bill, I do not have time to discuss in detail this morning. My written testimony provides more specific information and I would ask that it be entered into the record.

Mr. Chairman, I hope the Pell grants once again will be given top priority for funding increases in your bill. Last

year's increase of \$300, for a maximum of 3,000, was the single best step taken to help low-income students have an opportunity to obtain a higher education. Continuing the trend started by a Republican Congress to provide increases to the Pell maximum is a clear indication of the Republican commitment to this important program that helps needy students obtain a postsecondary education.

As in the past, I also hope the College Work Study and the TRIO will continue to be a funding priority of your committee. I really would like to stress the Work Study. I think the more we can do in that area, I think that is the best program out of all of these.

Finally, I will briefly mention the Employment Training and Literacy Enhancement Act of 1997. As you know, the House passed this bill last May and it is currently pending in the Senate. We understand the Senate will consider it shortly. This bill is an important step in addressing the Nation's long-term work force preparation needs by helping States and local communities to make sense out of our current confusing array of employment training and literacy programs.

The bill accomplishes long overdue reform, consolidating over 60 Federal programs through the establishment of three block grants to States and localities for the provision of job training services. This legislation is written to empower individuals, and not the Federal Government, to make decisions about their own lives and their individual employment and training needs. It will go far to help States and local communities to reform employment, training, and literacy programs and address the individual skill needs of their citizens, and it will go far to empower individuals to break the cycle of dependency that has plagued our country for far too long.

I trust that you will be able to conference this bill quickly and that the President will sign this legislation into law soon. I hope that your fiscal year 1999 appropriations bill will continue to provide sufficient funding for the important programs it reauthorizes.

Thank you, Mr. Chairman, for the opportunity to testify before you today. I would be happy to answer any questions that you may have.

[The prepared statement of Congressman Howard P. ``Buck'' McKeon follows:]

[Pages 2012 - 2016--The official Committee record contains additional material here.]

Mr. Porter. Well, that was perfect timing. Buck, I think we are tracking one another on each of the concerns that you have addressed in your testimony and, again, we are going to do the best we can. The allocation, obviously, is our limiting factor, but we will do the best we can within the resources we have. Thank you for coming.

Mr. McKeon. And all kidding aside, I seconded what the Chairman said as he was leaving.

Mr. Porter. Thanks, Bud.

I am informed by staff our colleague Frank Riggs has a child that is ill and he can't be here for oral testimony. We will accept his written testimony for the record at this point.

[The prepared statement of Congressman Frank D. Riggs follows:]

[Pages 2018 - 2023--The official Committee record contains additional material here.]

Thursday, April, 1998.

WITNESS

HON. JAMES P. MCGOVERN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MASSACHUSETTS

Mr. Porter. Next is Representative James P. McGovern of Massachusetts, and we are happy to see him.

Your timing was impeccable.

Mr. McGovern. I hope so.

I want to thank you, Mr. Chairman, for all the great work you do on behalf of medical research, which is very important to my area and also your great work on behalf of children's health, which is something I care very much about. I am going to abbreviate the testimony I submitted because I know you are backed up here.

I am here today seeking support for two vitally needed health care initiatives in western Massachusetts, which is in my district, and I am also here to urge that this committee provide a \$100 million increase for the Consolidated Health Centers program overall.

First, I request \$3 million for the health facilities construction program from the Health Resources and Services Administration for the recently merged University of Massachusetts Medical Center and Memorial Health Care in Worcester, now the largest provider of health care delivery in central Massachusetts.

These funds would help support an \$11 million renovation of UMASS-Memorial City Campus which operates and maintains programs dedicated to meeting the needs for ambulatory medical services, mental health services, and associated social services for Worcester's disadvantaged residents, and I am confident that the subcommittee's efforts to assist with this worthy project would have tremendous returns.

I also want to applaud you and the subcommittee for having increased the Consolidated Health Centers program by \$68 million in fiscal year 1998. It is my opinion every dollar our government invests in this program brings a return of incredible savings, health care savings, and it is for this reason I strongly urge the subcommittee to increase this program additionally for fiscal year 1999.

My second request represents an ideal example of how the consolidated health centers program would be successfully utilized, and I urge the subcommittee to provide a \$1 million health facilities construction grant to the Great Brook Valley Community Health Center to help them expand and meet the needs

of the growing number of patients they serve, more than double in the past. This facility serves the poorest population in the city of Worcester. I mean, close to 50 percent or more of the people they serve do not have insurance, and it is an incredible institution in the city of Worcester.

I know that there are budgetary constraints and I know everybody comes before you and asks for things, but these projects that I have just mentioned I would hope would get your consideration, and whatever you can do, I would appreciate it.

[The prepared statement of Congressman James McGovern follows:]

[Pages 2025 - 2027--The official Committee record contains additional material here.]

Mr. Porter. Jim, thank you. I have to say I am very pleased to be able to work with you on a bipartisan basis on children's health and I know of your very strong concern about the consolidated health centers and we will do our best.

Mr. McGovern. I appreciate it very much. Thank you very much, Mr. Chairman.

Mr. Porter. Thank you.

Thursday, April 30, 1998.

WITNESS

HON. STEVEN R. ROTHMAN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY, COMMUNITY HEALTH CENTERS

Mr. Porter. Next we are pleased to welcome Congressman Steve Rothman from New Jersey, who came before our committee and provided us--I guess it was last year, Steve--with very, very poignant testimony on autism, and we appreciate your counsel in this area.

Why don't you proceed with your statement?

Mr. Rothman. Thank you, Mr. Chairman. I too am grateful for your commitment to children's diseases and finding the cures for them, and I am profoundly grateful and appreciative of your bipartisan spirit and your kindness that you show to Members of both parties who come before you and this committee, so I am very grateful, Mr. Chairman.

Last year my brother and I came before you. My twin brother gave testimony about one of his three sons, the one who is autistic. His name is Jack. I have, since Jack's birth 7 years ago, met dozen and dozens of families in my district alone who are living with a child with autism. It is an excruciating, heartbreaking situation. You have a child who looks normal. If you saw this child on the street, you would say this is just a normal kid. The child is in his or her own world. There is all different levels of functioning. Five percent of them actually can be trained and educated, 5 percent. Yet we never know until the child is older, perhaps in his or her teens, whether they will be one of the 5 percent, so you are taking every single penny you can possibly get your hands on to invest in training

and tutoring on a daily basis, lest you miss something, lest you miss a time in that child's life when that bit of tutoring or education could have flicked the switch. So it is a constant state of unknown that goes on, and you are constantly wondering am I doing enough, have I found the right research, because 4 or 5 percent, they do realize this progress.

Four hundred thousand people in the United States are afflicted with autism. One in 500 children born today will be on the autistic spectrum. Though 5 percent will make strides with early intervention, the remaining 95 percent will never marry, never have a meaningful job, never live on their own, more than half will never learn to speak.

Until a few years ago, there was no hope for people with autism. For 30 years, psychiatrists thought it was an emotional problem or a problem of bad parenting. As a result of this tragic mistake, parents did not organize, medical research was not funded, scientists were not encouraged to enter the field, and a generation of autistic children was lost. While autism affects more people than multiple sclerosis, cystic fibrosis, or childhood cancer, autism still only receives less than 5 percent of the Federal research funding for these other decisions.

Recently, with your help, Mr. Chairman, and the help of your committee, the plight of autism and the need to vigorously pursue research in this area was recognized on a level never before achieved. Last year, the NIH announced it is undertaking a 5-year research effort focusing on neurobiology and genetics of autism, again with your prompting and your efforts.

Last summer, NIH held a conference aimed at improving autism research efforts. While we applaud these efforts as important first steps, we must recognize them as what they are: first steps. We need more research into the genetic, biochemical, physiological and psychological aspects of autism so that we can provide the more complete view of the disorder. Through this research we can identify genes and factors that cause autism, which can lead to earlier diagnoses and treatments or even prenatal gene therapy. In an age when important discoveries are being made in other diseases every day, we cannot allow autism, which affects so many Americans, to be left behind.

Mr. Chairman, there is still a major deficiency in the current spending on autism, despite last year's profound and terrific efforts on your behalf. I hope that this committee will again support strong report language encouraging the NIH to redouble its efforts in the fight against autism. I would encourage this committee to consider establishing Centers of Excellence for Autism Programs modeled after the very successful NIH centers programs for Alzheimers. These centers would provide an infrastructure that would allow clinical and basic research to take place in one site. In addition, training and demonstration of advanced diagnostic prevention and treatment for autism could be done at the centers. Data could then be shared between sites, and collaborative research projects could be organized across multiple sites.

If there is one thing everyone involved with autism is in agreement upon, it is that with continued medical research there will be treatment, there may even be a cure for autism.

It is only a question of time, energy, money, and will. I know that there are so many diseases that are worthy of your attention, Mr. Chairman, and that of your committee. I know that every disease of a child is a source of unbelievable pain for the parent. This human suffering is not a competitive sport or one to be ranked one against the other. But in autism, we have been so far behind for so long, and there is so much progress that was kept in abeyance because of our own ignorance of our own society. Now that we are opening our eyes, with the scientists' help for the first time, and we see how far behind we are, perhaps it is still appropriate to raise the level of attention and funding for autism which, as you know, will not only result in breakthroughs for autism but other neurological and brain disorders.

Mr. Chairman, again I want to thank you for allowing me to come before you and your committee, and I want to thank you again for your very sincere and widely acknowledged concern for childhood diseases and for your sincere and widely acknowledged reputation for bipartisanship.

[The prepared statement of Congressman Steven R. Rothman follows:]

[Pages 2031 - 2034--The official Committee record contains additional material here.]

Mr. Porter. Let me thank the gentleman for those very kind comments. Let me say it wasn't my leadership, but your own, that got us moving in the right direction on autism, and we learned a lot by listening to you last year and this year as well. And I think that is what made the difference. We are only responding to the things that we hear.

I have to say, as I listened to your testimony both years, it strikes me that there are the same kind of similarities between Alzheimers and autism. They both are such heart-rending diseases not only for the individual afflicted, but for the family. And you referred to the mirroring of the centers' approach for Alzheimers in your testimony concerning autism, so we are listening very carefully to what you say.

I would appreciate your giving us some suggested language on this for the report, and we will work with you and do everything we can do advance the cause. Thank you for your tremendous advocacy, Steve.

Mr. Rothman. Thank you, sir.

Thursday, April 30, 1998.

WITNESSES

HON. LEE H. HAMILTON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF INDIANA

HON. JOHN N. HOSTETTLER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF INDIANA, ACCOMPANIED BY JOHN MARVEL, CHAIRMAN OF THE BOARD OF THE INDIANA SOCIETY OF RADIATION ONCOLOGY

DR. ALLAN THORNTON, RADIATION ONCOLOGIST AT HARVARD MEDICAL SCHOOL

DR.WILLIAM SMALL, RADIATION ONCOLOGIST AT NORTHWESTERN UNIVERSITY
HOSPITAL

Mr. Porter. Next we are pleased to welcome our colleague from Indiana, Congressman Lee Hamilton, one of our favorite people in this institution. I am sorry; is Mr. Hostettler appearing with you? Are you all together?

Mr. Hamilton. Well we are all together on the project, I know that.

Mr. Porter. I am sorry. My staff informs me I should welcome John as well. With Congressman Hostettler is John Marvel, Chairman of the Board of the Indiana Society of Radiation Oncology; Dr. Allan Thornton, Radiation Oncologist at the Harvard Medical School; and Dr. William Small, Radiation Oncologist at Northwestern University Hospital. So we are having a full panel here.

Mr. Hamilton. Mr. Chairman, thank you very much. I ask that my statement be made a part of the record and I will be very brief.

We are requesting \$10 million to fund the Midwest Proton Radiation Institute at Indiana University in Bloomington. We are joined here by the gentlemen you have just introduced, who are the experts in this area, and who will discuss the project in more detail. I am delighted to work with my colleague, Congressman Hostettler, to advance this project.

I don't pretend to be any kind of expert here, Mr. Chairman, but proton therapy, as I understand it, focuses a beam of accelerated protons on certain cancer growths and can effectively radiate tumors in a way that conventional radiation cannot.

The proton beam focuses cleanly on the tumor, causing little damage to surrounding tissues and organs.

There are proton therapy facilities in Massachusetts and California. We don't have any in the Midwest. I think these gentlemen will be able to indicate the success of these facilities on the two coasts.

The Midwest Proton Radiation Institute in Bloomington involves a unique collaboration of physicians and scientists from throughout the Midwest providing access to proton therapy treatment of various cancers. It will serve over 60 million people in the Midwest, including my State of Indiana and your State of Illinois.

The advantage of this is that the Indiana University already has the proton accelerator on site. The cost of upgrading it, I think, is \$20 million. We are asking for \$10 million from the Congress. An additional \$10 million will be made available from non-Federal sources.

If you had to have a new facility, it is my understanding the estimate would be about \$65 million dollars for that facility.

This is an enormously important project for us and, more importantly, for Illinois or for Indiana, just for millions and millions of people I think who would benefit over a period of years, of course.

So it is a project of personal interest to me, it is of great importance, and I want to urge you to do what you can, with all of the competing pressures upon you, to help us out.

Mr. Chairman, I am involved in another hearing, so I will

excuse myself, with your permission, and perhaps Congressman Hostettler would like to join in as well.

[The prepared statement of Congressmen Lee H. Hamilton, John N. Hostettler, John Marvel, M.D., Allan Thornton and William Small, Jr., follows:]

[Pages 2037 - 2042--The official Committee record contains additional material here.]

Mr. Porter. Thank you, Lee.
John.

Mr. Hostettler. Thank you, Mr. Chairman and members of the committee, and I thank my colleague, Congressman Hamilton, for being here as well and lending his bipartisan support to this very important project.

Mr. Hamilton capsulized very well what we are going to hear about with regard to the expertise and experience of this fine panel that includes Dr. John Marvel, chairman of the board of the Indiana Society of Radiation Oncology; Dr. Allan Thornton, who is a radiation oncologist at Harvard Medical School; and Dr. William Small, who is a radiation oncologist at Northwestern University Hospital.

Mr. Chairman, if it please the committee, I lend the rest of the time of Mr. Hamilton and myself to the testimony of the following witnesses.

Dr. Marvel. Mr. Chairman, It is a privilege to be here.
Thank you.

Mr. Porter. Are you Dr. Marvel, since you don't have name plates?

Dr. Marvel. I am Dr. Marvel.

It is a great opportunity to give testimony for a facility that will provide care for millions of citizens in Indiana, Wisconsin, Kentucky, of course your State, and surrounding midwestern States.

You already have my written testimony. I will try to be brief.

We formed a consortium of physicians and scientists throughout the Midwest to put together the Midwest Proton Radiation Institute, MPRI. The purpose is to bring to the Midwest access to proton therapy, which is currently only available on each of the coasts, in California and Massachusetts.

When compared to conventional X-rays, if I could present myself as a target, ordinary X-rays enter and deposit most of the dose and then fall off with depth. Protons, conversely, enter at a lower dose, build up to a maximum right where you want them to stop, and fall off so there is no exit dose. You focus your dose at the tumor and you minimize collateral damage.

Proton beam therapy is a preferred treatment choice at selected treatment sites, including base and skull tumors, ocular tumors, paraspinal tumors, some head and neck cancers and some brain tumors. It is useful for many pediatric cancers. There are promising results published for prostate cancer and macular degeneration. There is active interest in treating lung

patients with it. If widely available, it would undoubtedly be the treatment of choice at many additional sites.

We learned long ago as physicians and radiation oncologists, we are limited in the doses we can safely deliver to cure patients. We are forced to accept some acute and chronic side effects in the hopes of better local control. Many patients live with acute effects during therapy. A lot of them have chronic side effects, such as dry mouth, outer bowel habits, loss of sexual function, limited respiratory reserve. A few patients suffer the ultimate complication, death. My wife's first husband, treated for Hodgkin's Disease, developed bowel complications, a fistula peritonitis, and death.

A good friend, John Kiger, was cured of testicular cancer, but a decade later developed a radiation-induced cancer in field, and he died. Proton therapy minimizes the dose to healthy tissue and minimizes this risk.

As a physician in Indiana, my patients have no regional access to this form of cancer treatment; therefore, with the others on this panel, I am asking you to provide \$10 million to be matched by non-Federal funds for the conversion of the cyclotron facility at Indiana University into a proton therapy facility so that citizens in the Midwest have the same access to this form of cancer treatment as do individuals in South Africa, Japan, Europe and the east and west coasts of our great Nation. I also have written testimony from Dr. John Cameron, the director of the Indiana University Cyclotron, that I would like to submit concerning the concept of funding and organization. Thank you.

[The information follows:]

[Page 2045--The official Committee record contains additional material here.]

Mr. Porter. Thank you.

Dr. Thornton. I am Dr. Allan Thornton, a candidate for medical directorship of the Midwest Proton Radiation Institute, and I appreciate the time you have given to convey our support for the Midwest Proton Radiation Institute.

The MPRI is a consortium of physicians and oncologists really from the entire Midwest, extending from Wisconsin down through Kentucky and into Pennsylvania, who have banded together to support the conversion of a cyclotron machine on the Indiana University campus in Bloomington into a truly state-of-the-art facility to provide proton therapy.

The most prohibitive elements in the establishment of a proton beam facility is the cost of the accelerator itself, and in the case of the MPRI, Indiana University is offering that accelerator to the consortium for use in the proton therapy treatments. This dramatically reduces the cost from an estimated \$65 million to about \$20 million. As the State of Indiana has been targeted for half of this need, our request is for an appropriation of an additional \$10 million from the NCI to allow the conversion of the cyclotron facility to begin.

As you will recall, the facility I am familiar with, the Massachusetts General Proton Therapy Facility, was initiated

through the efforts of this very subcommittee in 1989. Language was included in the fiscal year 1990 Labor-HHS-Education appropriations bill which targeted the National Cancer Institute, which lauded the potential for proton beam therapy as a treatment option for certain tumors and vascular diseases. Funding was included in each of the subsequent appropriation bills to construct and equip the proton facility at Mass General Hospital, and I am pleased to announce the facility will open in September of this year.

As a bit of insight into the need for this facility, we currently at Mass General have a 5-month delay in the treatment of our patients waiting for beam time, which will be reduced with the new facility's opening in September. However, patients from the Midwest are not served by this facility, and I know this well through my own patient referral basis.

During my tenure at the University of Michigan and at Mass General Hospital, my colleagues have increased the 4-year control rates of paranasal sinus tumors and base-of-skull tumors by 30 percent with the use of proton beam therapy, and this has been peer reviewed in journals. My colleagues have performed dosimetric studies, comparative studies, on patients with pediatric malignancies and gynecologic malignancies, indicating approximately a 50-percent reduction in the normal tissue irradiation that is achieved with the use of proton therapy over conventional therapy, which should reduce significantly the risk of second malignancies many years later. This is only possible with particle beam proton therapy.

While we appreciate the many competing priorities your subcommittee faces, we request the inclusion of the \$10 million in the fiscal year 1999 Labor-HHS-Education appropriations measure to aid in the conversion of the accelerator on the Bloomington campus into a facility dedicated to the treatment of cancers and other afflictions with the use of proton beam therapy. Thank you.

Mr. Porter. Thank you very much, Dr. Thornton.

Dr. Small. Thank you for the opportunity to testify and support the Midwest Proton Radiation Institute. I am William Small, Jr., M.D. I am an attending physician at Northwestern University Medical School and assistant professor at Northwestern University in Chicago.

My support for the MPRI centers on the fact of the establishment of this facility in close proximity to Northwestern would allow my patients access to this proven form of cancer therapy. From a practical point, it is very difficult to get a patient to go to Boston, even if we note the critical importance for their treatment, as the travel and lodging costs are sometimes quite prohibitive to patients.

As Dr. Thornton indicated, MPRI is made up of a consortium of physicians and oncologists from throughout the Midwestern States. Because of this consortium approach, patients receiving treatment can remain under the supervision of their physicians in St. Louis, Chicago, Detroit, Louisville and other midwestern cities.

This unique model creates a joint center, operated by several institutions, and offers an enormous and continuing increase in knowledge and expertise.

I am also supportive because the facility will generate

useful clinical research. Partnership agreements between the MPRI facility and other institutions in the region will allow for comparison studies between proton radiation therapy and a much a wider range of treatment options, and I know Northwestern would be very happy to participate.

The accelerator to be used in this facility was originally developed through the National Science Foundation over many years and has concluded the studies for which it was designed. However, in addition to the existing equipment, the large body of top scientists from around the world who can enhance research programs at the MPRI remain on staff. Using these medical accelerated research experts, the MPRI will be able to conduct studies to create a more powerful and adaptable facility than is currently available in the U.S.

This consortium approach also encourages a wider sharing of resources among the institutions located within the region. These factors, combined, will accelerate the development of this technology in a manner that increases the rate of technology transfer and affordability reduction, while at the same time expanding access to this treatment.

The fact the facility could be up and running with just a \$10 million Federal investment far short of the \$60 million-plus needed to develop a new functional facility, is a definite advantage. I hope you will be able to provide the \$10 million through the NCI to make the facility a reality for those who are geographically isolated from the existing U.S. proton beam facilities. Thank you very much.

Mr. Porter. Thank you, Dr. Small.

Can I ask John several questions? First of all, is the cyclotron accelerator, once it has been converted, is it then to be exclusively used for this purpose, or will it continue to have other research applications? In other words, will it be devoted solely to proton therapy, So from then on it would be used just for that purpose?

Secondly, let me ask: Is this therapy covered by Medicare and Medicaid payment and insurance; in other words, is it established therapy that is included within those reimbursable structures?

Dr. Marvel. It has been paid for on each coast by Medicare. We talked with the carrier in Indiana and the plan is to basically bill at the same rates we would be billed for conventional therapy and it is our understanding it will be covered.

Mr. Porter. I talked yesterday with some physicians and scientists about boron therapy for malignant brain tumors. Is there any relationship between this type of therapy and that type of therapy?

Dr. Thornton. Perhaps I better answer that. Not particularly. The theory with boron neutron capture therapy is the neutrons are trapped by chemicals that are taken up by tumor cells within the brain, the theory being that neutrons will preferentially be distributed within the brain in that area. Protons, ounce per ounce, are no better or worse than conventional therapy. It is their accuracy of delivery and dose delivery that is crucial and it is proven in protons, in over 35 years of work at Mass General Hospital, whereas boron neutron capture therapy is still very much in the developmental

phases and we do hope it will be successful, but it is far from having been demonstrated as a success.

Mr. Porter. Is there any possibility, and I understand the need to verify its application, but is there any possibility that that application to malignant brain tumors could be expanded in the future to other types of cancerous tumors or cells; in other words, is this therapy--I didn't ask them, so I will ask you--a possibility of a much broader application?

Dr. Thornton. You are asking about boron. They are looking at that currently in the melanoma trial, looking for skin cancer; there are compounds that are preferentially uptaken in the skin, and they are looking at that in an initial phase with melanoma.

Mr. Porter. If that therapy were to develop along those lines, would it be a possibility to replace proton radiation therapy, or do they do entirely different things?

Dr. Thornton. They are really entirely different. The difficulty is most of the tumors that we treat with proton therapy are next to critical structures. When I treat patients with head and neck tumors, paranasal sinus tumors, I am treating 1 to 2 millimeters away from the visual system. We have very little likelihood of developing an agent, a drug, that will be so preferentially absorbed in one tissue and not in another, but one and two millimeters apart. I think the likelihood of BNCT, which is what we call it, effectively doing the same job is unlikely.

BNCT will be used, if it is successful at all, in relatively global tumors, over a large area, that are very resistant to conventional radiation therapy. Proton therapy is effective for tumors that are responsive to regular radiation, but for whom you cannot give a high enough dose of regular radiation because you are next to critical structures. A 10-percent increase makes the difference between cure and failure in these patients, and that is the patient population we are really speaking of with proton therapy.

Mr. Porter. See, John, I get a medical education if I listen carefully.

Mrs. Northup.

Mrs. Northup. Mr. Chairman, I would like to speak on behalf of this and submit the testimony of Dr. Joes from the University of Louisville. He happened to have treated my daughter at the Brown Cancer Center. He was the radiation oncologist, and unfortunately she had conventional treatment and will always suffer the lung, the heart, the back-of-the-neck damage that comes with that kind of treatment. I would like to speak on behalf of this and pass this testimony on to submit.

Mr. Porter. Thank you, Mrs. Northup.

One final question. I wasn't sure that I understood correctly. Does NCI already have money--have they already put money into this project?

Mr. Hostettler. My understanding is no.

Mr. Porter. But they have put money in the past in your project.

Dr. Thornton. In the Mass General project.

Mr. Porter. So there is a precedent for this type of investment through NCI?

Mr. Hostettler. In fact, there has been significant investment recently in a machine from Belgium, is my understanding, to be placed at Mass General, and that was new machinery, new hardware going in place. This project, much of the hardware is already in place, and a significantly smaller investment by NCI will be necessary to make this a reality for the Midwest.

Mr. Porter. John, thank you very much. Let me thank each of the physicians that have appeared here today, and as I say, I have learned a great deal and we will do our best to be responsive.

Thursday, April 30, 1998.

WITNESS

HON. JAMES E. CLYBURN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF SOUTH CAROLINA

Mr. Porter. Next is Congressman James E. Clyburn of South Carolina, who will testify on several projects of interest.

Mr. Clyburn. Thank you, Mr. Chairman. Mr. Chairman, I appreciate the opportunity to appear before you today on behalf of a project which is of vital importance not only to the Sixth District of South Carolina but the entire State.

I am here to ask you to consider an appropriation of \$358,000 for a research initiative for child and family studies at University of South Carolina's College of Social Work.

The center is the State's premiere research and training unit in family dynamics. The research initiative the center seeks to develop will increase knowledge of intrafamily violence, lead to more effective treatment and prevention of violence, and increase faculty capacity for further research.

This research will focus on the following three types of intrafamily violence: child abuse, spouse abuse, and elder abuse. The objective of the research will be to study violence in the family over the lifespan, with an ultimate goal of developing appropriate treatment methodologies to address these forms of intrafamily violence; thereby, this treatment will allow us to respond to this societal ill in a more cost-effective manner.

Mr. Chairman, in my written request to you, I submitted more detailed information on this proposal, which I instructed the university to prepare and I would refer your staff to that package. If you need additional information beyond that, I would be happy to provide it to the subcommittee.

Mr. Chairman, I would be personally grateful for any consideration you may extend to this worthwhile and dynamic initiative.

[The prepared statement of Congressman James E. Clyburn follows:]

Mr. Porter. Well, thank you. That is the project that you are interested in testifying on behalf of today?

Mr. Clyburn. Yes.

Mr. Porter. We have several here. This is the one you are focusing on?

Mr. Clyburn. Yes, sir.

Mr. Porter. Thank you, Congressman Clyburn. We will do our best, as I say, to respond; and this is obviously a very important area.

Mr. Clyburn. Thank you very much, Mr. Chairman.

Mr. Porter. Thank you.

Thursday, April 30, 1998.

WITNESS

HON. BILLY TAUZIN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF LOUISIANA

Mr. Porter. Next we are pleased to welcome our colleague from Louisiana, Congressman Billy Tauzin, Chairman of the Telecommunications Subcommittee of Commerce. And Billy, it is good to see you.

Mr. Tauzin. Mr. Chairman, I noticed the chairs here have ashtrays on the back of them. I thought that was rather strange.

Mr. Porter. That is strange. I didn't know that.

Mr. Tauzin. In the Commerce Committee, we are struggling with the tobacco issues ourselves.

I wanted to thank you for allowing me to come today. I am accompanied today by my office manager and her husband who have particular interest in my comments to you today, because their son has recently been diagnosed with Friedreich's ataxia. Recently, as you know, Dr. Varmus appeared before this Congress and testified and used Friedreich's ataxia to make his points about NIH funding. He used Friedreich's ataxia as his focal point because, in fact, this is a genetic disorder that is going to leave this young boy incapacitated. By the time he hits his twenties, he will be in a wheelchair, all his muscle functions are eroding, and it is genetic. It is a genetic disease that affects Cajuns at 2 1/2 times the national rate, and it is because of this particular feature of the people I represent, for whom I come, the Cajun population of Louisiana, that I appeal to you today.

We are really in a unique position with the unique Cajun population, which is still very closely organized and associated in South Louisiana. The oil and gas industry allowed them to sort of live together for many, many family generations and not to have to move to seek employment or locate somewhere else, and the particular community is one that is ideal for genetic studies.

There are a number of diseases in the Cajun population--cancer, diabetes, heart disease, as well as Usher syndrome and Friedreich's ataxia. Many diseases affect our population at 2 1/2 times the national rate, and these genetic connections are what Dr. Varmus talked about.

In that regard, I would like to bring to your attention

again this unique scientific opportunity in terms of examining genetic diseases in the context of studying through the history of these families inside Louisiana the connection between these diseases and genetics and the gene pool.

In that regard, I am here, along with five members of the Louisiana delegation, to petition you for money for the LSU Medical Center in New Orleans, \$6 million in 1999, and then \$3 million per year for the following 3 years, for the establishment of the Acadiana Medical Center to indeed assist NIH and the whole medical community in the identification of the genetic connection to the diseases.

LSU Medical Center is committed to the goals of the center. They are going to provide the space and a million and a half a year in support of it. It is again an extraordinary opportunity to find answers to these genetic problems, not only answers as to how they arise, but how to deal with them; and perhaps even, before this young man is totally incapacitated, perhaps some cure.

Recently in Washington, you recall, members of the general disorder community, families who are suffering Friedreich's disorders and others, were here in Washington, and we saw firsthand what an awful impact it has on so many families in our country.

This center in New Orleans is indeed exactly what Dr. Varmus talked about when he came and testified, when he talked about the need to broadly identify the impact of genetic disorders in our society, and it could lead to important work across America in the discovery, the diagnoses, the treatment, and eventually the cure of many of these diseases.

I also wanted to put in a good word for the community health centers and funding, Mr. Chairman. I am strongly in support of your efforts to increase funding for the Consolidated Health Centers Program by \$100 million each year, bringing the total to \$926 million.

I represent rural America along the bayous in Louisiana. There are places I represent, sir, that you can't get to from here; you have to go somewhere else before you can get there. Most of my communities are along bayous that sort of stretch out like fingers of a hand, and you can't get from here to there without going back up the bayou and going down the bayou. It is very difficult to reach many of these Cajun populations on the edges of bayous and swamps and marshes in south Louisiana, and the community health centers provide incredibly important medical assistance to those families. Health care prevention--disease prevention, rather, and those sorts of things are coming to the bayou communities because of community health centers.

Use of emergency rooms are way down. Federal funds to the centers in fact, in several of the centers, is decreasing each year because of the success of the center movement. And I would just encourage you, to the extent you can, to assist in encouraging the establishment and success of the centers across rural America. In the bayous, they are literally essential to good health care practices for our citizens.

[The prepared statement of Congressman Billy Tauzin follows:]

Mr. Porter. When you were talking about the bayous, I was thinking how vast this country is and how different it is, and each of us have to understand that the needs of our constituents may be different than the needs of each other, and be prepared to respond to that.

Can I ask one question about the Friedreich's ataxia, and that is has the gene been identified yet? It has been.

Mr. Tauzin. About 2 years ago.

Mr. Porter. And is there followup work being done to see what can be done to change that so that the disease can be avoided?

Mr. Tauzin. In fact, Dr. Varmus testified that in some very--I mean, work that was not even connected to this, they discovered valuable information. The protein has been identified that is lacking in the genes. They were doing some other research. It was with yeast. They were doing yeast research, and Dr. Varmus--this was the whole center of his testimony before Congress when he came. What they found in the yeast research was yielding incredibly valuable information with reference to the protein that was identified, that was connected to what is missing in the cells because of the defect in the genes. And so they are beginning to make the links.

I guess what I am trying to tell you is when you have a population like that, that is closely associated, 2\1/2\ times the national average in all these diseases, you have a unique laboratory to find out what the links are all about and how to cure them.

Mr. Porter. It is also fascinating, the serendipitous nature of research and how people look for one thing and find something they weren't looking for at all.

Mr. Tauzin. So there is hope. I mean, here is a young family. Rachel has served me in Louisiana, has come to Washington to serve our office here, and she is my oldest in seniority employee going way, way back, and she is much younger than her years with me would tell. But the bottom line is she married here in Washington, only to find out this fellow she married had Cajun genes, and one of their children is diagnosed with this genetic disorder. And we learned through her about it. We learned how Cajuns all over my district were suffering at abnormally high rates in this disorder and other disorders.

So this young family's experience, as they watch their son lose his bodily functions--he can no longer ride a bike and has great difficulty riding--they are watching him deteriorate. It is something our office is--all of us are experiencing together with them, and it has brought to us in a very personal way how urgent the need for this research to advance is.

It is possible, Mr. Chairman, if we do this right, if we find these connections, it is possible we can reverse this and have this young man lead a normal life instead of seeing him continually wither away. I can't tell you in a personal way any more than that, we are all experiencing the suffering of this child and the suffering of this family and, through them, the

suffering of so many other Cajun families and Americans. And here is a potential way of reaching a solution for them and I don't want to pass it up.

Mr. Porter. We will do our best to respond to you. I feel very strongly that, as resources become available, we really want to increase funding for biomedical research. There are so many areas like this one where we are on the edge of making the discovery that really will make a difference in terms of the effect on others, and we will do our best to respond.

Mr. Tauzin. You have been very kind. Thank you, sir.

Mr. Porter. Thank you.

Thursday, April 30, 1998.

WITNESS

HON. RICK LAZIO, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK, THE NATIONAL SERVICE CORPS, AIDS DRUGS ASSISTANCE PROGRAM, RYAN WHITE CARE ACT, AND HIV/AIDS RESEARCH

Mr. Porter. Next we are pleased to welcome Congressman Rick Lazio of New York to testify on the National Service Corps, AIDS Drug Assistance Program, Ryan White Care Act, and HIV/AIDS research.

Your timing was impeccable. We were just about to go to the next witness.

Mr. Lazio. Thank you, Mr. Chairman.

I appreciate very much the opportunity to testify before the committee, and I want to begin by complimenting you for the fine work you have done in some difficult circumstances over the last few years as you manage what I think is one of the more important portfolios in the appropriations 602(b)'s.

As you mentioned, Mr. Chairman, I am here to just ask for your continued assistance. You have been a strong supporter of virtually all these programs as we move toward the cycle, and I know we don't know exactly what we are going to be dealing with until we have the budget adopted, but there are certain programs that I think have been remarkably successful and deserve the committee's full support.

Let me list, first of all, in no particular order, frankly, but let me acknowledge that the National Senior Service Corps, which is responsible as the umbrella organization for many different programs, particularly the foster grandparent program, which has been leveraging volunteerism--and if you have had the opportunities I have, to go into a classroom to see a foster grandma or grandpa connect with these kids, they provide assistance and allow the teachers to focus on some special needs that they have in the classroom. It gives incredible meaning to the seniors. I have had more seniors come to me and say, ``It gives me a reason to get up in the morning, I feel loved and important.'' It provides incredible, I think, leverage to our educational opportunities, over 119 million hours of service to our communities, and it is estimated about 1.5 billion dollars is saved through the use of this volunteerism. It is also expected new funding will generate 14,000 new volunteers, with about 3.5 million hours of work.

Let me also ask if you would continue to provide your

support and your leadership, which you have in the past, for cancer research to the National Cancer Institute, certainly our premier global institutions in terms of research. I know without your leadership, we would not be in a position where we are today, where we are on the verge of numerous breakthroughs.

I want to just touch on a few that I know that you have been incredibly supportive of: the human genome project and the gene therapies that really hold extraordinary promise in terms of our ability to find what has been described as a repair manual for the human condition.

On Long Island, we have an extraordinarily high instance in mortality rate of breast cancer, so we are very focused on this issue. This is a national problem, it transcends breast cancer to ovarian cancer, prostate cancer, lung cancer, which continues to be the number one killer, and the progress being made through NCI deserves our continued support.

The next program, which I would ask for the committee's support would be through the ADAP program, the AIDS Drug Assistance Program. One of the frustrations, as we move toward these cocktails of medication, these integrated therapies that are showing extraordinary promise for people who are living with the HIV and AIDS, is that the cost of the program often is a very significant barrier to treatments. So some people know it is there, that they can benefit from it, it can save or prolong their life, and yet they can't quite afford to do that.

Many States have stepped forward, New York is one of those that I think has been cooperative on this, and I would ask the committee to continue to support this program. Through this program, we establish a network of providers for treatment, and especially important are the new protease inhibitor drugs which are widely credited with reducing the AIDS mortality rate.

Last year we had about a \$21 million shortfall. Last year about 26 States implemented emergency measures due to financial shortfalls. Ten States are closed to new enrollment and two States remain without protease inhibitor coverage. So there is some very extreme need in the case of some of these areas, some of these States.

The next program that I ask the Chairman's support and the committee's support on is an FDA hotline. Last year, as part of the FDA reform bill, I was able to have a bill that I had filed, an amendment adopted, which would create a one-stop information hotline over at NIH to provide the public with the latest information about scientific research efforts designed to combat all life-threatening illnesses. It would provide a human contact for people who are interested in clinical trials, not just publicly financed, but privately financed clinical trials, to give them information how they could participate, what is going on, and what hope is out there. I will be forwarding to the subcommittee a strategic plan with specific funding requests in the coming days to try and help with that.

And, finally--I am trying to move through this quickly and trying to be sensitive to your time--Job Corps, which has in the past enjoyed the Chairman's support and the committee's support, has enabled more than 69,000 economically disadvantaged young people to receive education, vocational training, social skills training, and job placement assistance. About 80 percent of its graduates are placed. It is, I think, a

very fine alternative to what might otherwise be the alternative in the streets.

I would say just briefly, in visiting Job Corps centers-- and I don't have the advantage of having one yet in my district, but I will say that one in the south Bronx is really doing some fantastic work--I have spoken to some of the young people there who never knew how to open a checking account, do a job interview, interact with a boss, resolve conflicts with colleagues, the things many young people take for granted but because of their upbringing and the communities in which they are raised, they don't have that.

One young woman said, ``The only time I go home anymore is to go to a funeral for one of my friends,'' and that is not the environment we want for our young people to be part of a global work force.

So I ask for your continued support for these programs. I think they are extraordinarily important. I know you have shown leadership on these in the past, I salute you for that and I ask for your sustained support of these programs.

[The prepared statement of Congressman Rick Lazio follows:]

[Pages 2062 - 2066--The official Committee record contains additional material here.]

Mr. Porter. Rick, thank you very much for your testimony, and we will do the best we can within our allocation. I talked to John Kasich yesterday about a budget resolution, and he tells me it is still a long way off. So while we are going to complete our hearings next week, we may have to wait quite a while before we can mark up.

Mr. Lazio. You can count on my support, Mr. Chairman, to ensure your allocation is properly protected.

Mr. Porter. Thanks, Rick.

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Thursday, April 30, 1998.

WITNESS

HON. ROBERT A. WEYGAND, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF RHODE ISLAND

Mr. Porter. Let me tell members that we are proceeding in order of the time slots assigned to members, and if a member does not arrive or is not available when they are called, then they have to go to the end of the list. So we will proceed as we have been on our list.

Congressman Robert Weygand of Rhode Island, who has been very patient here.

Mr. Weygand. Thank you very much, Mr. Chairman. I want to thank you for the opportunity to testify again before you. I have submitted testimony in greater detail for the staff and committee's review. I would just like to highlight a couple points, because I know your time is of the essence and I know a couple of my colleagues here would really like to testify as

well.

I would like to first start off talking about an issue, not just in the State of Rhode Island but all throughout the country. Telemarketing fraud, you have heard and I know the committee members have heard, costs consumers tremendous amounts of money every year. Approximately \$40 to \$50 billion every year, the FBI indicates, is a result of telemarketing fraud and scams throughout the country. Over 50 percent of those people that are scammed are over the age of 55, which means approximately \$15 to \$20 billion every year.

There are stories, horrendous stories, that I could tell you about from Texas to California to Rhode Island; but just a couple. Just last year, a man in Florida was put in jail for a scam that robbed elderly citizens in eight States throughout the South of over \$1 million, elderly citizens. A 74-year-old woman in Texas recently lost \$74,000 to phony telemarketers; as well as in Rhode Island a little while ago, a prisoner, while in prison serving time, scammed elderly residents in six other States of \$95,000.

We have some very good laws with regard to, once we catch the people, putting them in jail. The problem we have is trying to alert elders in terms of an education and awareness program on how to prevent telemarketing fraud. We have been working with the Office on Aging within HHS to create a bill, 3134, which I think we have around 50 or so cosponsors on it right now. What this would do would be providing \$10 million--and that is why I am asking you for this support, Mr. Chairman--in the bill, \$10 million to the Department for purposes of conducting extensive outreach programs to senior citizens across the country, to educate them about the dangers and also some of the techniques and tricks that they can use to prevent scamming.

And when it is costing us, our taxpayers, billions of dollars, to invest \$10 million throughout the country is really a very, very small amount, although it is substantial with a very, very tight budget, but it will bode well for this Congress to show to the public that we really want to prevent these. Catching them afterwards is fine, but when elders give out all of their money--and many times it is their life savings on some of these scams--hoping they are going to be able to have a very good final few years of their life, and they lose it all, we need to educate them about telemarketing scams. We hope you will support the provision that will provide for another \$10 million within the Office of the Administration on Aging.

Another area, very important, I was very happy to hear my friend and colleague from Long Island talk about is Job Corps. Forty-six of the States have Job Corps centers. We are requesting that you fully fund the administration's request on Job Corps.

Rhode Island is one of only four States that does not have a Job Corps center. We are now under application to the Department of Labor for one. But for all the reasons Rick Lazio mentioned, it is an important program to get our youth into; first of all, knowing how to go to work in the morning; secondly, giving them the kind of skills they need to be able to become a productive part of society. Job Corps centers really do that in many different ways. By fully funding the

administration's request, we as well as three other States will be able to have Job Corps centers that will truly help many intercity youth in ways many of the programs that are out there could not.

The last program I would like to leave you with is home delivery meals. My wife and my children and I have worked many years with Meals on Wheels and many of the other meals programs. Most of these are staffed by volunteers, RSVP programs, and a host of others. We find that there are waiting lists on nearly 41 percent of all of our meal sites throughout the country, waiting lists for seniors who really do need nutrition programs.

This is really important for a lot of reasons. First of all, having reasonable nutrition programs is good for the seniors, but many of these programs are the first warning signs of what may be going wrong in a home or with some of our seniors. They help us prevent people going into a nursing home by alerting to some of the health care centers and other people what is going wrong with our seniors, and so therefore, they help them with home care and less expensive means than putting them into nursing homes.

The second thing many of the meal sites do is provide an emotional and cultural and social support for seniors that in many cases they don't have. They do not have sometimes the family support, and they rely upon the sites not only for nutrition, but for social interaction and emotional support. It is a wonderful, wonderful program that yields us many dividends in terms of other things we as taxpayers don't have to pay for by having these problems.

So I ask you on that program, Mr. Chairman, to fully fund that as well, and sincerely appreciate your time for allowing me to testify here today.

Mr. Porter. These are all important priorities. You said there is authorizing legislation introduced on telemarketing fraud?

Mr. Weygand. Yes, it is called the PASS Act, Protection Against Senior Scams. But we have not moved very far on the authorization, Mr. Chairman; that is why it would be so important to have it within this piece of legislation. And quite frankly, I am not so sure it will move alone by itself.

Mr. Porter. We can't put authorizing language in without the authorizers telling us we should.

Mr. Weygand. But the authorizing bill may exist within the Administration on Aging. They may be able to do it if they have the additional money without authorization language; that is what our hope is. If there is money in there to allow them to do it, they think we could be able to--if we don't get the authorizing language, and we hope we will, they believe we may be able to do it even with the additional money. We have been working closely with the Administration on Aging on it.

Mr. Porter. Why don't you have the administration send us a letter telling us under what authority they could act if that is the case? That would help us.

Mr. Weygand. I will be happy to do that, Mr. Chairman. Thank you very much.

Mr. Porter. Thank you very much.

[The prepared statement of Congressman Bob Weygand

follows:]

[Pages 2070 - 2075--The official Committee record contains additional material here.]

Thursday, April 30, 1998.

WITNESS

HON. J.D. HAYWORTH, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF ARIZONA

Mr. Porter. Next our colleague from Arizona, Congressman J.D. Hayworth. You have been very, very patient.

Mr. Hayworth. Mr. Chairman, I thank you very much, and I would also like to point out the patients of some of my very important constituents who join us today; not to violate any protocol, but I think we should recognize some exceptional young people who are here under the Close Up program from both the Loop and Rough Rock community schools of the Navaho nations. Would you stand up to be recognized today? I love to show off my constituents who are here.

Mr. Porter. We are delighted to have them and we welcome each one of them.

Mr. Hayworth. Thank you, students, and thank you, Mr. Chairman. I hope it wasn't too great a violation of protocol, but they are very important, and I think for purposes of my testimony today, they put a very human face on a very real need.

I am pleased to have this opportunity to testify today, Mr. Chairman, on two very important programs to the people of the Sixth District of Arizona: impact aid and community health centers.

Mr. Chairman, on behalf of all the members of the Impact Aid Coalition, I want to thank you for your continued support for the Impact Aid Program and for helping us secure \$808 million for fiscal year 1998.

As you know, the coalition recently sent you a letter in support of \$887 million in funding for the Impact Aid Program for fiscal year 1999, and I hope you will help us secure that amount. Later today, members of the coalition will testify on the importance of the Impact Aid Program, and instead of rehashing their testimony, I would like to focus my remarks, as I did last year, on section 8007, the school construction portion of Impact Aid.

Mr. Chairman, as you know, my district is unique because it has the largest Native American population in the 48 contiguous States. The Navaho nation, from which my special guests come today, stretches across four States and is roughly the size of West Virginia, and is one of the largest and most economically challenged of the sovereign Indian nations, with staggering unemployment rates which can run as high as 50 percent, depending on the season. Education is the only way for the students here with us today and so many others on the reservation to escape a life of poverty.

The other 7 tribes, I represent, in my sprawling district

face similar hardships and depend on impact aid to help educate their youth.

Mr. Chairman, part of our treaty obligations to the Indian tribes includes educating these children. Without impact aid, the Federal Government cannot live up to its treaty obligations. I support the coalition's goal of securing at least \$887 million for this important program. While that money will help educate impacted children in my district, I think we all can establish the fact that they need to learn in a safe and healthy environment.

Many school buildings on the Navaho nation and on other Indian reservations are cracking, leaking, and, simply stated, falling apart. They are in decrepit conditions, and frankly, most of these buildings should be condemned. Nevertheless, students must be educated even if their schools are sadly in substandard conditions.

I recently examined five school districts--Chinle, Red Mesa, Sacaton, Pinon, and Window--to determine what their school construction needs are. And, Mr. Chairman, I am glad you are sitting down. The total need was an incredible \$179 million. And, Mr. Chairman, sadly, some of the problems include the use of so-called temporary buildings for the last 30 years. It is simply unacceptable.

The coalition is asking for an increase from \$7 million to 16 million in section 8007 funds. This increase will help alleviate some concerns, but the reality is this program hasn't received increases in the past, and sadly, it will hardly make a dent in the sad state of federally impacted schools in my district and across the United States.

Now, ladies and gentlemen, for the record, I note the average school in the U.S. costs nearly \$6 million to build. With the coalition's request for 16 million, we would only be able to build the equivalent of three schools each year. There is certainly a need for more than three schools a year in my district alone. Section 8007 must be increased substantially if we are to effectively educate our children on Federal lands in a safe and healthy environment.

I respectfully request this subcommittee fund Section 8008 and Section 8007 of Impact Aid at a minimum of \$25 million for fiscal year 1999. With this increase, we could start to repair, renovate, and build new schools that are badly needed in my district and across the country.

On another issue, Chairman Porter, I am pleased to testify before you in support of an increase of 100 million for a model program that is the epitome of what a government program should be: the Consolidated Health Centers Program. I come before you today on behalf of the citizens of the Sixth District to thank this committee for past investments made in the program.

Over the last 2 years, you have provided health centers with \$68 million in funding increases. As a result of your wise generosity, three new health centers were fully funded and constructed in my district. Thanks to the consistent investments made by this committee, Arizona has 11 health centers serving 150,000 people. And for my medically indigent constituents, this means no longer having to drive significant distances to receive affordable medical attention that quite often has literally made the difference between life and death.

In addition, each community health center serves as a prime example of how a Federal program should work in three important ways: cost-effectiveness, local control, and quality.

First of all, when it comes to cost-effectiveness, health centers primarily serve minority and low-income populations; but for less than 76 cents per patient per day, health centers provide preventive service to uninsured and underinsured, even in the face of language and cultural barriers.

Second, local control. The Federal Government has provided seed money to empower communities to establish their own local boards to govern these health centers, thus linking the community to patients and local citizens who in turn have a real voice in the works of the center.

And, third and certainly not least in this, quality. Mr. Chairman, studies show that Medicaid beneficiaries who are regular patients of health centers have fewer chronic diseases, use the emergency room less, have fewer costly complications of diseases and ailments, and have fewer hospital admissions than those Medicaid patients who are not regular users of health centers. However, without significant increases in grant funding, the utilization of community health centers has the potential of overwhelming the ability of health centers to provide quality care.

As Dr. Marilyn Gaston, director of the Bureau of Primary Care, pointed out to this committee, 5 percent of health centers are bankrupt and between 5 and 10 percent more soon will be, due to fiscal constraints. Health resources and services administrator, Dr. Claude Earl Fox, indicated that it is his professional judgment that health centers need a \$200 million increase in fiscal year 1999 to meet the demands.

Mr. Chairman, simply stated, you face a daunting challenge, and that is perhaps the understatement of this legislative session. But on behalf of my constituents, I would like to once again thank you for allowing me this opportunity and honor to highlight the importance of providing this program with an increase of \$100 million for fiscal year 1999, for you responding to the challenges of Impact Aid, and again for you so graciously and warmly welcoming my constituents to today's testimony.

[The prepared statement of Congressman J.D. Hayworth follows:]

[Pages 2079 - 2082--The official Committee record contains additional material here.]

Mr. Porter. J.D., thank you very much for your testimony. I have been slowing us down by commenting on everybody's testimony. I will have to keep quiet for a while and just listen. Thank you. We will do our very best.

Mr. Hayworth. Thank you, Mr. Chairman.

Thursday, April 30, 1998.

WITNESS

HON. ELIZABETH FURSE, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF OREGON

Mr. Porter. Congresswoman Elizabeth Furse of Oregon to testify on the subject of education.

Elizabeth, nice to see you.

Ms. Furse. Nice to see you, Mr. Chairman. Thank you. I am going to try to rush through this. I know we have a vote.

Every year, I have come before your committee to support education and ask for your support, so there are a number of programs I am just going to touch on that I am very, very supportive of. Federal funding for Head Start. We just recently received notice that the State of Oregon was going to give additional funding for Head Start because of the Federal help that they had received, so that matchup is so important.

School construction initiatives, of course, I am very, very supportive of. We have seen some problems with a real danger in our schools. I would request that the committee fund civic education. There is a Senate level of \$7 million, and this would be very helpful for programs such as We the People. That is a program that really teaches kids civic values and it has been one we have had in Oregon a lot of experience with.

TRIO, Mr. Chairman. I always come and talk about TRIO. In Oregon, our successes are very, very impressive. We had over 3,800 students engaged in TRIO. TRIO not only exposes kids to college, it gives them some special skills and some help where they need a little extra help.

The President's request is \$583 million and if that is possible, Mr. Chairman, we would love to see that. Just unfortunate about Upward Bound is that so many kids qualify and so few can actually use it. In one program alone, 500 children qualified; there were only 55 slots, so it would have been great for them.

Job Corps. I am very supportive of Job Corps. We have a Job Corps center in Astoria, Oregon, and over 80 percent of their graduates receive jobs, go to the military, or advance in education.

We have a number of financial aid issues which obviously are so important for students going to college. A Pell grant--I would like to urge the committee to increase the Pell grant to 3,100, although I would love to see it go to the authorized level of 4,500. That would be great.

State-issued incentive grants. We use those in Oregon tremendously. We have a lot of students who are involved in that. Portland State University is requesting \$750,000 in special purpose funding.

Obviously we use a lot of these urban community service grants. They have made a great improvement in the lives of young people and I hope that the \$10 million will be included.

Now, Mr. Chairman, I would like to focus on one program. As you know, I support you tremendously in trying to increase medical research funding, especially in diabetes, but in order to complete the picture for medical health improvement, we need to invest in infrastructure. The health facilities program of the HRSA Administration is the avenue for your committee.

We have a program in Oregon, the Oregon Health Sciences Program, that has managed to pull together about \$30 million in

donated services, in donated land. It is going to be a wonderful program. It is a women's health program and it will be the full continuum, both research and care; a Federal investment of just \$3 million. A one-time investment will help us complete this whole picture. Thirty million will come from our community. And it is an ideal model of HRSA funds. It is a private-public partnership, and I would like to have your attention to that.

Those are just a few of the issues, Mr. Chairman. I don't want to take more of your time. I will submit a full statement, but again I want to thank you for all you have done in the past for the First Congressional District of Oregon. We are deeply grateful.

[The prepared statement of Congresswoman Elizabeth Furse follows:]

[Pages 2085 - 2088--The official Committee record contains additional material here.]

Mr. Porter. Thank you, Congresswoman Furse. Elizabeth, you covered a lot of ground there. They are all important priorities, very definitely.

We do have a vote on. We have Congressman Cliff Stearns next; then Congressman Davis; then Congresswoman Slaughter; then Congresswoman Thurman.

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WITNESS

HON. CLIFF STEARNS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF FLORIDA

Mr. Porter. Cliff, good to see you. Please proceed.

Mr. Stearns. Thank you, Chairman Porter. I am pleased to be here and want to thank you for allowing us.

I come here, quite simply, to ask for increased funding for the NIH budget. I think when we look politically across the spectrum, you say either you are a fiscal conservative or you believe in more Federal spending, but I think the longer you are here in Congress, you start to realize that depending upon the issue in your congressional district is perhaps more important than anything because you are trying to represent those people.

I just am here to say that I think we need an additional 7 percent a year increase for the NIH. When you look at the overall NIH budget compared to foreign aid, they are almost comparable in size, and I think the NIH budget should be a lot higher, and I can't understand why we continue to fund NIH at, I think, a very tepid pace. I am suggesting, as well as our Senator from Florida, Connie Mack, to increase NIH funding. I hope, having said all that, you will realize the enormous implications that the NIH funding would have for Americans, particularly for senior citizens, Florida, who are coming into

the Medicare program, and in the area of the genomics, which is one of the most exciting and promising developments in molecular medicine. Once a map of the human genes is made available within the next few years, we will be able to make comparisons with our own genetic, unique genetic blueprint.

Mr. Chairman, this will herald in a new era of computer collaboration with molecular medicine to develop a DNA chip, transferring the functions of the human genome to a computer chip to be run for comparison for diagnostic and treatment purposes against our own genetic map. The NIH is funding the genome center.

I have a bill dealing with genetic privacy. I am chairman of the Genetic Privacy and Health Records Task Force of the Commerce Committee, and I can't tell you, after having been to NIH, how important it is for you to consider increasing funding for the NIH, and I think perhaps my brevity will make the point. Thank you, Mr. Chairman.

Mr. Porter. Cliff, I can't agree with you more. I think you are exactly on point, and we are going to do the best we can to do exactly what you and Senator Mack want us to do.

[The prepared statement of Congressman Cliff Stearns follows:]

[Pages 2090 - 2092--The official Committee record contains additional material here.]

Mr. Porter. Off the record for a moment.

[Discussion off the record.]

Mr. Porter. The subcommittee will stand in recess.

[Recess.]

Thursday, April 30, 1998

WITNESS

HON. DANNY K. DAVIS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF ILLINOIS

Mr. Porter. The subcommittee will come to order.

We continue our hearings with Members of Congress and are pleased to welcome our colleague from Chicago, Representative Danny Davis, to testify on federally qualified health centers.

Mr. Davis. Thank you very much, Mr. Chairman.

Let me thank you for the opportunity to be here this morning. I certainly want to thank you and the committee for the support that you have given to the programs that I am going to touch on over the years.

I am here this morning to ask that we increase the funding for our community health centers by at least \$100 million, and I do so not only on the basis of the research and statistics, but also on the basis of my personal experiences with community health centers, with which I have been associated for more than 30 years now. As a matter of fact, I had the good fortune to work in one, become the member of a board, and ultimately to

become president of the National Association of Community Health Centers. So, I have traveled around the country and I have seen them extensively, and I have seen what they bring to especially underserved communities and what they bring to poor, rural, migrant, urban, inner-city communities all over the country. They have proven themselves to be the very best that we have seen in terms of the ability to deliver quality health care to large numbers of poor people. All of the indicators suggest that, all of the statistics suggest it, and what we need in order to keep them viable and keep them moving is, in fact, an increase.

I was pleased to hear the testimony of my colleague from Arizona, who just testified a few minutes ago about the need for the centers in areas that he represents. So we would hope that we could get at least 100 million additional dollars that would ultimately save at least \$1.2 billion, according to all of the estimates that we have, because now we are going to catch people at the early stages of their illnesses, we are going to do prevention, we are going to keep them out of the hospital, and we are also going to revitalize and redevelop these communities, because community health centers are economic tools that are used in many instances to help redevelop communities that otherwise would lie stagnant. So we appreciate the opportunity to convey and share this information and this position.

I would also urge that we increase funding for the TRIO programs, for the Pell Grant programs, and for medical research. I was pleased to be at an affair not very long ago for the opening of a new research center at the Rush Presbyterian St. Luke's Hospital. When they talked about support they had received, they mentioned you most prominently and indicated that I somehow or another was being thrown into that same category, although being a new Member of Congress. So, I am very pleased to join with you in supporting these very worthwhile ventures, and I appreciate the opportunity to testify this morning.

Mr. Porter. Danny, thank you.

[The prepared statement of Congressman Danny K. Davis follows:]

[Pages 2095 - 2098--The official Committee record contains additional material here.]

Mr. Porter. I was at a community health center in the city, and I think it probably was in your district on Erie, just west of the Loop, and they were doing wonderful things. They were doing outreach through volunteers and bringing people in who wouldn't otherwise be served, and the level of quality care that they were providing was just wonderful. So I am very impressed with what community health centers are doing, and we want to obviously continue to give them the kind of support you are suggesting.

Mr. Davis. Thank you very much. That was the Erie Family Center, and they are indeed doing well. Thank you.

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WITNESS

HON. LOUISE McINTOSH SLAUGHTER, A REPRESENTATIVE IN CONGRESS FROM THE
STATE OF NEW YORK

Mr. Porter. Next is Congresswoman Louise Slaughter of New
York.

Ms. Slaughter. Thank you.

Mr. Porter. Who returned just in time.

Ms. Slaughter. In the nick of time. I have disappointed
several of my colleagues with my timing, Mr. Chairman.

I appreciate this opportunity to testify before you again.
Before I say anything, I want to say to you how grateful I am
to you for your work as an outspoken advocate for the most
vulnerable in this society, and the work you have done for
homeless, the elderly and low-income families is very
important. You have also been a very good friend for those of
us who are trying to bring new attention to neglected issues
like women's health, and I thank you for that.

I am going to be very brief because I know how busy you
are, but there are a number of things I wanted to bring to your
attention.

As the head of the Task Force on Women's Health in the
House, I wanted to talk about the Office of Women's Health at
the NIH. It was established in 1990 to coordinate, facilitate
and improve the quality of women's health research, and it
certainly has, but I am concerned that since its inception, it
really has not received a meaningful budget increase, and
particularly as the prominence of women's health has increased
and women are taking more active interest in their own health.

The administration is requesting 19.2 million for this
office for 1998, which is an increase of only 4 percent over
the previous fiscal year, and I would like to urge the
subcommittee to provide a budget increase proportional to that
increase given to NIH as a whole. We are way behind.

Federal research into the effects of the drug
diethylstilbestrol are still yielding important insights into
the action of environmental estrogens on the human body. As you
know, that awful drug was given to millions of pregnant
American women between the years of 1938 and 1971 to prevent
miscarriage, but it didn't; it cause cancers in their children.
So we would really appreciate for you to continue that funding.

Eating disorders are a growing problem in our Nation,
particularly among young women, and I appreciated the
committee's inclusion in last year's conference report the
language encouraging the National Institute of Mental Health
and the National Institute of Child Health and Human
Development to coordinate the eating disorders research.

I am also grateful that last year's report instructed the
Secretary of Health and Human Services to pursue eating
disorders education efforts. When we have children as young as
7 and 8 years old going on diets, we have a critical problem.
It is a serious health problem. So I am sure that once again
you will show your concern.

Colorectal cancer, Mr. Chairman, is another neglected health issue. Ninety-seven percent of the persons diagnosed can be cured. The difficulty is getting people to be screened. We need to make sure that women understand it is not just a man's disease, but it strikes men and women at equal rates, and it is the number three cancer killer of the Nation's women. It has to have renewed attention, so we are working very hard to raise the education program from 2.5 to 5 million. We think we will save a lot of lives with that.

Menopause is another issue we are just beginning to look at. Aging women still don't feel able to discuss it, even with their own doctors. Women need to have full factual information about normal changes that can be expected with menopause and the treatment that is available to provide relief for some symptoms. So we would appreciate some attention on that research as well.

I have some information about the National Technical Institute for the Deaf, but you have been kind enough to hear me on that before, and I know you like them as much as I do.

One of the things I do need to talk about is your support for the homeless children's bill, and, Mr. Chairman, although that is kind of an orphan bill, your support of that has meant the world to me as author of that bill in 1986, as part of the McKinney Act. We are asking for 30 million this year, which is still not very much, but the little money we have given, we have reduced the number of homeless children now to 14 percent. We need to reduce it to zero.

We found the homeless education program is working. It is improving regular school attendance, and grades, and scores in high school graduation and GED completion rates, and we hope this may be a phenomenon of the past and that now that the employment is good, the economy is good, we are going to see fewer and fewer families that are homeless.

I want to show you how this program worked. His name was James. He was a 10th-grader staying with a family friend while his mother and sister stayed in a shelter. It was all women, so James couldn't stay there. He had to stay with a friend, and he didn't go to school at all, and he was ill. When he was finally able to go to school, he was tired and coughing, his clothes were soiled and ripped, and he didn't have any books or pens or anything to write with.

The vice principal called in the person in charge of homeless education, Mr. Sayles, and in accordance with the bill that has been written, Mr. Sayles helped him get an appointment with a physician at a neighborhood health clinic. They let him pick out clothing, alarm clocks, school supplies and hygiene products that they had put aside for children, and he is now a more productive student as a result of support received from the adults around him. And that is just one of the many ways this program provides education, but it makes sure children are looked after and have the opportunity to get educated.

I think it is an important component of welfare reform, because we think children who are obviously unhealthy, uneducated and untrained are probably going to grow up to be tomorrow's welfare recipients, and if we can do anything to stop that--and, frankly, every American child should be allowed to get a good education in the United States. We can't leave

any part of that population out, and homeless children have been neglected.

In regard to the 21st Century Community Learning programs, they are very important, have done wonderful things already, but there are going to be \$40 million in it this year, and there are over 2,000 applications already, and out of that, only 13 percent will be funded this year, so we really need to increase that. I urge you to consider increasing the funding to 200 million for year 1999, because we need to expand the after-school programs which promote safe and nurturing activities for young people during the nonschool hours.

We all know the crime rate in this country goes up every day between the hours of 3 and 7 p.m. when children are out on their own. If we can offer them positive alternatives, and give them some tutoring, and make sure they have homework and are ready for next day's school, and give them something besides a television set for company, we will be doing a great thing for the future generations. Art projects are there that help them develop their minds.

So that is the request I have for you today, Mr. Chairman, and thank you again for your unfailing kindness.

[The prepared statement of Congressman Louise M. Slaughter follows:]

[Pages 2102 - 2104--The official Committee record contains additional material here.]

Mr. Porter. Louise, that is a pretty good list. I have to tell you, and you know this, when we first talked, this is probably 3 years ago now, about homeless children's education, frankly, I was very skeptical about needing another program and thought they could be served within existing programs. And you convinced me very, very quickly that this is probably a prime example of how, since they don't have any homes, they don't have any school districts, and they fall right between the cracks, and you have been exactly right in that, and we appreciate your tremendous leadership in that area.

Ms. Slaughter. I thank you for that.

Mr. Porter. As well as so many others.

Ms. Slaughter. I appreciate that. But it is true, too many school districts, if you don't live in that school district, you can't go there. So a lot more children need our help, and I know you will be there to help us, and thank you.

Mr. Porter. We are going to do our best.

Ms. Slaughter. Thank you very much.

Mr. Porter. Thank you, Louise.

Thursday, April 30, 1998.

WITNESSES

HON. KAREN L. THURMAN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF
FLORIDA

DR. STEPHEN SOMLO, ALBERT EINSTEIN COLLEGE OF MEDICINE

Mr. Porter. Representative Karen Thurman of Florida testifying on polycystic kidney disease.

Ms. Thurman. Mr. Chairman, thank you.

I just want to note that that exchange just a few minutes ago was so good to hear. So many times we do come up here with preconceived ideas, and I think that is a shame, and if we keep our minds open, it is amazing what we can do. So what Louise had to say about you says a lot about who you are, and it says a lot, and I just wanted you to kind of know that.

Mr. Chairman, we have talked a little bit about this issue before on polycystic kidney disease. It certainly is one that I deal with on an everyday basis with my husband. He now has had a transplant, so we have been one of the fortunate groups. We also have two children, though, and because it is genetic, and this is kind of a late disease to find out what is going to happen, but there is the potential either one of my children might have it, or they might not have it at all.

The other issue from a standpoint of just policy is looking at the amount of people that have PKD, it is about 600,000 people. It can attack as many as 12.5 million worldwide, and it costs the American taxpayers about \$1.5 billion annually.

I really want to emphasize this because I was a little bit disturbed after I found this out--this committee really did do some good work in this area, and they specifically asked NIH and NIDDK to redouble their efforts in this area, and that, in fact, did not happen. I know that you don't and I agree that we shouldn't be earmarking, because none of us want to see, quote, the disease of the month, but on the other side, you did make it clear we should have some redoubling. That has not happened, and I hope we can let the folks know there is some real reason why that was done that way.

But I think also in this process sometimes that we don't always see the end results of things, or, you know, you always hear about what people want and not necessarily what has happened since you have helped them along the way, so today I have Dr. Stephen Somlo, actually from Albert Einstein College of Medicine, is accompanying me, and he is going to give you kind a little update as to where we are and why the redoubling of these efforts are so important.

[The prepared statement of Congresswoman Karen Thurman follows:]

[Pages 2107 - 2109--The official Committee record contains additional material here.]

Dr. Somlo. Chairman Porter, my name is Steve Somlo, and I am a physician scientist conducting research in polycystic kidney disease at the Albert Einstein College of Medicine in the Bronx. It is my honor to come before you to report on the progress that I and my colleagues in the PKD research community have made in recent years.

It is my goal to convince you of the promise of this field and of the merits of redoubling efforts to ensure continued growth of funding for PKD research. The recommendation is mentioned that your committee made as recently as last year.

Whether it is the high blood pressure or the acute ataxia, severe debilitating pain, that results from the rupture or bleeding of cysts, PKD patients have a decades-long losing battle with consequences of their genetic makeup. PKD is the third leading cause of renal failure in the U.S., and our available therapies of dialysis and transplantation have their own spectrum of complications.

As a physician, my goal is to prevent disease progression, not just to treat its ravages along the way, yet as a physician treating PKD patients, all I really can do is the latter.

Ten years ago, I resolved not to be only a nephrologist in PKD patients, but also an investigator working to discover treatments to change the course of polycystic disease. To my great satisfaction, this past decade has seen tremendous scientific progress in PKD research. I have had the good fortune of being part of this progress supported by three NIH research awards, one of which I obtained through the last round of RFA for PKD.

The application of the advances of the human genome project to the problem of PKD had been the focus of my studies. Genome chromosome 16 that accounts for 85 percent of PKD families was discovered in 1993, and its gene product, the proteins, heretofore unknown proteins, are currently under intense investigation.

In 1996, my laboratory succeeded in identifying a second gene for PKD accounting for the disease in the remaining 15 percent of families. It also uncoats an unknown protein. Working with investigators at John Hopkins, we were able to show that the two proteins, the first and second genes for polycystic kidney disease, interacted directly; that is to say, they talk to each other through direct physical contact inside cells. This discovery has profound implications for an understanding of PKD.

Most recently, my group has inactivated the mouse copy of the PKD gene and in the process has successfully reproduced the human polycystic disease state in the mouse. This achievement will enable us to study PKD in ways that we cannot do in humans. The mouse model has already taught us PKD occurs by a mechanism that had previously only thought to be operational in cancer syndromes, the so-called two-hit hypothesis.

PKD patients inherit one bad copy of the gene from their affected parent and one good copy from their other parent. With the passage of time, the good copy also gets inactivated in some cells in the body, and this is the second hit. These individual cells with the two bad copies of the PKD gene are the ones that multiply and go on to form cysts.

The fundamental change in our understanding of cyst formation has caused us to rethink approaches to therapeutic strategies. Slowing the occurrence of these second inactivating mutations in the next 5 to 10 years could change the course of PKD in affected patients.

The PKD mouse model also provides a system in which we can develop and test novel directed therapeutic strategies without exposing patients to any risk. Therapy, whether it is small molecules, that is to say drugs, or gene replacement that shows promise in treating the disease in the mouse can subsequently be pursued for safety and efficacy in human subjects, and to my

mind, this is the definition of translational research from the bench to the bedside. In my opinion, the polycystic research community is poised to make that trip within the next decade.

Perhaps our most willing partners in all this research have been the PKD patients themselves. They supported us both financially and through organ donations, and they did it for themselves and for their children.

So, Mr. Chairman, when we are moving so fast and getting so close, I hope that we can convince NIH and NIDDK to share in this enthusiasm and increase funding for polycystic kidney disease research.

That concludes my statement.

Mr. Porter. Doctor, I don't have your name before me. Can you tell me it again?

Dr. Somlo. Steve Somlo, S-O-M-L-O.

Mr. Porter. Well, thank you, Dr. Somlo. We appreciate your testimony.

Karen, I wasn't aware until you told me that they have not proceeded. I have asked staff to find out so we will know, and we will follow up on that and do what we can to straighten that out.

Thank you very much for your testimony.

Thursday, April, 1998.

WITNESS

HON. DON YOUNG, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF ALASKA

Mr. Porter. Don, you have been very, very patient and long-suffering in waiting for us to get to your point in the testimony. Why don't you proceed.

Mr. Young. Thank you, Mr. Chairman. I would like to submit the testimony of Doug Bereuter on the same subject.

Mr. Porter. It will be received.

[The prepared statement of Congressman Doug Bereuter follows:]

[Pages 2112 - 2113--The official Committee record contains additional material here.]

Mr. Young. I ask unanimous consent to submit for the record my written statement.

Mr. Porter. Without objection.

Mr. Young. Number one, Mr. Chairman, since you have been Chairman, and when you were Ranking Member, we have asked for support from this committee on the Allen Ellender Fellowship Program, and the Close Up Foundation administers the program. This program is probably the most--I think the most rewarding program for young people across this Nation. In Alaska, we have had 9,000 students since 1979 attend this program here in Washington, D.C. Today, I have 55 Close Up students today from all over from the State of Alaska that get a better understanding of what you and I are doing, what the committee members are doing, and how the system works. And I think that

is crucially important now during this period of what I call cynicism about politics. I have had a lot of follow-up conversation with students through the correspondence and personal discussions about their attitude towards our government and towards the workings of Congress, and I have never had one that came away negative.

So there is a request for a \$3 million from you to continue this program, this scholarship program, or fellowship program, and I would suggest it is probably the best money invested. Every time I come to testify before you, I listen to all the other people testifying, and they all have worthwhile projects and worthwhile suggestions in asking you for the request of money. But I am speaking now of the future of those people who will lead this Nation, and the more we can get away from cynicism, the better off we are.

The Close Up program really does the job it was set out to do, and that is expose young people to the better parts of our government, the United States Congress, of course the administrative end of it, and the executive branch and the judicial branch.

So I can only say that without the money that I am requesting, a lot of the students across this Nation would not be able to attend. It is not a freebie, it is matched money. There is a lot of effort put forth by each student. Some of our students in some of my other areas have to go out and raise their dollars. They do a good job, but without this money, a lot of the students would not be able to come down to Washington, D.C. to see us operate.

With that, Mr. Chairman, I just want to thank you for your efforts, and I guess I can afford to be patient when it is a worthwhile project.

[The prepared statement of Congressman Don Young follows:]

[Pages 2115 - 2116--The official Committee record contains additional material here.]

Mr. Porter. I think Close Up does a super job, and I think all of us put young people who come to Washington at a very high priority and want to give them a good feel about what we do, and I think Close Up really helps us do that. I know that the money that they receive from our grant is only a small proportion of the money they raise and provide for young people, and I want to do my best to provide and share support for their very important mission.

So we thank you very much for testifying and for your patients and for your advocacy for Close Up.

Mr. Young. Thank you, Mr. Chairman.

Mr. Porter. Thank you.

Thursday, April 30, 1998.

WITNESS

HON. JOHN F. TIERNEY, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF

MASSACHUSETTS

Mr. Porter. Congressman John Tierney of Massachusetts testifying about a building at Salem State College; is that correct?

Mr. Tierney. How are you, Mr. Chairman?

Mr. Porter. Fine, thank you. How are you?

Mr. Tierney. Fine. I thank you for giving me this opportunity to speak before your committee and you in particular. You and I have had some involvement in the past with regard to the comprehensive schools, and I applaud you for working to make sure that that project went through.

The public schools, I think, are critical to the backbone of this country and to our moving forth as individuals in society, but also economically. It is in that regard that I come before the committee today, because just as we are supportive of our public schools, the elementary and the secondary level, I think there is a place for us to be somewhat helpful and supportive at the college level. Salem State College is indicative of that.

I come before the committee today asking for \$4.8 million for so-called smart building work to be done at Salem State College in Salem, Massachusetts. This Federal money would be used to help toward the construction and equipment cost of that project.

In the reauthorization of the Higher Education Act, H.R. 6, I am pleased to say that we were able to get language in establishing a mechanism for Title III schools for the participation of the Federal Government in such projects.

Smart buildings, if I can just define them, make provision for computer technology to be incorporated in the planned construction of a building, and that computer technology might be for multiple ports, laptops in every classroom, allow access to computer network and Internet. The classrooms' computers have wiring for hardware and software necessary to use the technology in every aspect of instruction; connects the faculty office with the college's computer network and Internet; implements computerization of the campus security, janitorial services, heating, ventilation and air conditioning; and makes available student services through kiosks in the corridors, giving them information on financial aid, class registration and tuition payments; and essentially brings us into the next century and lets us be competitive with those private institutions that are able to get enormous endowments to put these types of facilities together so we can have students that go to public colleges that qualify into Title III to have the same type of facilities going forward.

In this particular project, the State has stepped forward and given substantial funds for the purchase of the site, which Salem State College is expanding. They have given an enormous amount. There has been a private effort to raise money for this. Salem State will be moving its business courses and section over to the performing arts area and is going to have an incubator business segment of the college campus that allows businesses to come in and start up, use the students as interns, and get new businesses going, use the technology, and have the students benefit in that way.

I think not only will the college benefit, obviously, and

the students that attend, but the business community and the North Shore around Salem will be able to get people out for the work force developed and ready to go to work and to enhance the number of small businesses that have been generating so much for the economy around there. And that is really what this is about, trying to get an opportunity for students to come out ready to go to work at well-paying jobs and businesses in the area to benefit from having those students trained.

There has been a greatness of cooperative efforts. Salem State College has been around since 1854. It started as a normal school, and we have been trying to define that term since then. It is now a fully accredited 4-year college; has been for some time. It is an institution that has an enrollment of 9,200 full-and part-time students. It is well-known nationally for some of its courses in geography, in nursing, in education and in business, as well as other areas of social work and the sciences and liberal arts.

I would ask this committee give serious consideration to participating in that with the \$4.8 million. I think it will be a worthwhile project, and I think it will be an indication of what we can do to share a role in making sure that people have the kind of education we talk about down here a lot to move forward and be productive.

[The prepared statement of Congressman John F. Tierney follows:]

[Pages 2119 - 2120--The official Committee record contains additional material here.]

Mr. Porter. John, this is going to be authorized in the Higher Education Act that we are dealing with right now.

Mr. Tierney. That is correct. The language is in there, and it looks like it will be authorized, and it is a good opportunity.

Mr. Porter. I can't speak for the East, but in the Midwest, normal schools were schools to train teachers.

Mr. Tierney. That's exactly what it was in Salem, and we have expanded out considerably since then. It still maintains a good national reputation, particularly in early childhood education.

Mr. Porter. This is a fascinating concept as you described it. You know, sometimes you think you are born too late.

Mr. Tierney. I went there and I graduated from there, so it is particularly interesting for me to see the school expand in this way and have those kinds of opportunities for students. I went there for the reason a lot of Title III schools exist: It was the only choice that we had. It was the place I could afford and the opportunity that we could do. I really think it would be a shame for us to miss this opportunity to let those students have the kind of educational facility that others who go to tremendously well-endowed schools get on a regular basis.

Mr. Porter. Thank you for your testimony. We will again do our very best.

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Thursday, April 30, 1998.

WITNESS

HON. SUE W. KELLY, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

Mr. Porter. Congresswoman Sue Kelly of New York, testifying on the Impact Aid Program, particularly on section 8002.

Mrs. Kelly. Thank you, Mr. Chairman.

Mr. Porter. Sue.

Mrs. Kelly. I thank you for providing me with the opportunity to testify this morning. While there are a number of important programs under your jurisdiction that I would gladly speak to, I want to focus my remarks on two specific issues that concern my district. The first one is Impact Aid; the second one is Lyme disease research.

First, I would like to thank you, Chairman Porter, for the sensitivity you have shown to the importance of funding the Impact Aid Program. Without this program, specifically the section 8002 program, the Highland Falls-Fort Montgomery School District in Orange County, New York, could not keep its doors open.

The school district is literally surrounded by Federal and State lands and the Hudson River, leaving no room for expansion. About 93 percent of the lands within the school district are nontaxable, making it increasingly difficult for the school system to raise the revenues necessary to provide our children with the quality education they deserve.

Three years ago, the school system was struggling, laying off teachers, closing buildings, neglecting maintenance and curriculum development. The district had protracted contract issues with its teachers, had a staff with a very low morale, was experiencing strained relationships with its neighborhoods and partners. The children were using outdated textbooks, and test scores were really suffering.

What a difference a couple of years makes. Thanks to the good work of this subcommittee in the past 2 years, I come before you today to tell you about a true success story, a story of renewed community spirit and children learning in a better, cleaner, safer and healthier environment. Because of the committee, this subcommittee and this Congress, the commitment you have made to us over the past 2 years to fund the Impact Aid Program, I can today tell you all about the new textbooks and the new teachers development program that the school has that I have been able to implement. I can tell you about the new social worker they were able to hire that has affected the greater drug intervention programs that they have; the two new advanced placement classes; the eight new elective classes. This summer is the first summer they are going to be able to offer summer school for remediation.

In addition to the academic improvements, the school system has been able to address some long-neglected physical plant improvements as well. New tiling has been installed, and 20-year-old carpeting has been replaced, which, according to our school nurse, has significantly reduced the number of asthmatic incidences.

The list of improvements goes on and on, but please don't take my word for it. I want to quote briefly a summary of the Educational Vistas Incorporated, who conducted independent evaluations of the Highland Falls-Fort Montgomery Central School District curriculum. They do this every 2 years, and this is what they said: ``The Highland Falls Fort Montgomery School District is a decidedly different district than the one visited 2 years ago. Today, while still facing a number of challenges, it has a `renewed' teaching staff, many of whom are actively engaged in self-reflection, professional growth and school improvements. It emphasizes collaboration and partnership at the building level and at the district level.''

Still quoting: ``A caution, there is no `miracle' performed here. The district has only begun a journey long delayed and long neglected, but it has begun strongly. The district should now commit to moving to the next level.''

These results were largely due to the renewed commitment that Congress made to the Impact Aid Program. Through the Impact Aid funds provided the school district, we have placed these schools and especially the children who attend them on the right track. It will take additional funds and time to get them where they should be, but look at what a difference 2 years of funding have made in my school district.

I join with all of my colleagues in the Impact Aid Coalition in requesting \$887 million for the Impact Aid Program in fiscal year 1999, which represents a very modest increase in funding over 1998. I also would urge this subcommittee to ensure this increase is spread fairly to ensure that all impacted communities, including land-impacted communities, receive the funding that they need and deserve.

Finally, Mr. Chairman, I would like to touch upon the importance of funding for Lyme disease research. I speak not only as a Member of Congress, but as one who has suffered from Lyme disease. This disease has reached record levels in 1996, with 16,000 diagnosed cases, and probably approximately 100,000 unreported cases, because it is very difficult for the doctors to diagnose these cases.

I strongly urge the committee to support increases in the CDC and NIH funding. I also ask that the committee encourage both agencies to renew their commitment to the study of emerging diseases, such as Lyme disease. In Congress we talk about reducing the cost of health care in this country. What we need to realize is that the most effective way to do so is to invest in medical research and prevention and education.

Mr. Chairman, those affected with Lyme disease feel abandoned. As a resident of one of the most Lyme-affected areas, I have a responsibility to see this disease gets the attention it deserves so we can stop the suffering and find a cure. Please help us.

Thank you very much, Mr. Chairman.

[The prepared statement of Congresswoman Sue W. Kelly follows:]

Mr. Porter. Sue, that was an excellent statement. Let me say that it wasn't the leadership of this subcommittee, it was your leadership and your advocacy for funding for Impact Aid, and particularly 8002, that has made a difference in that school district, and we want to obviously put the resources there to help you make that school district even better, and we will do our best to do that.

Mrs. Kelly. Thank you very much.

Mr. Porter. Thank you, Sue.

Thursday, April 30, 1998.

WITNESS

HON. HAROLD E. FORD, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF TENNESSEE

Mr. Porter. Next, Representative Harold E. Ford of Tennessee testifying regarding the Job Corps.

Harold, nice to see you.

Mr. Ford. Good to see you, Mr. Chairman.

I won't take up much of your time because I know, as a new Member, that you bring the experience and the knowledge and the commitment in more amount of time than I have been actually been on this Earth, being 27.

You are one of the main reasons, if not the principal reason, that we have a Job Corps Center in the 9th District, with the help of my father over the past few years, and I thank you for your leadership there and thank you also for your leadership on the floor as it relates to all education issues.

I would only just really reemphasize or reiterate some of the points that I am certain you are fully aware of. Job Corps Centers throughout this Nation have really served as a force for economic and educational development for a group of young people, many of them who look like me, young African American males who have been really written off largely by a large segment of society and have been labeled as incorrigibles. But this program, as you well know, sir, has worked and has been able to reach out to many who have been locked out of the mainstream and in some cases have felt hopeless that their chances of integrating or finding some long-term participation has really been nil.

Seventy-eight percent of Job Corps participants are high school dropouts; 66 percent have never held a full-time job; 73 percent are between 16 and 19 years of age. Although Job Corps has resources to assist fewer than 2 percent of eligible youth, of that 2 percent, 80 percent leave the program to join our work force or to further their education.

I had the privilege of visiting my Job Corps Center some several weeks back during one of our most recent recesses and had an opportunity to visit with teachers who indicated it was the most pleasant teaching environment, and they have never seen students more eager to learn and to absorb than what they have experienced. These are teachers with vast teaching experiences and educators with vast teaching experiences, all attesting to the fact that Job Corps Centers work.

My Center--I shouldn't say my Center, the Center that you helped create, Mr. Chairman, is one of only three Centers in this Nation that trains young people in the computer service-computer repair industry for those jobs. The President later today will announce a 4.2 percent increase in GDP growth and credit this expansion with the robust demand for computer goods.

You know better than anyone, Mr. Chairman. I just hope that this committee is able to fund the request the administration has asked for, the increase of \$61.4 million.

Lastly, one of the reasons, I think, that they have asked for the increase, as you well know, Mr. Chairman, is the need to meet some of the child care and Head Start challenges as many of the young people move toward trying to better themselves and trying to cost us less on the front end than they will on the back end.

With that I say thank you and hope that you are able to, as you have been able to in the past, gain this committee's support and this Congress's support.

[The prepared statement of Congressman Harold Ford, Jr., follows:]

[Pages 2130 - 2132--The official Committee record contains additional material here.]

Mr. Porter. Harold, thank you for your advocacy and your father's advocacy and others who strongly support Job Corps. We think the same thing about this program as you do, that this really works for kids that are most at risk in our society.

The thing that all of us have to do, because there is so much negative news on our television screens every night, is to get the media to look at things that work and are really inspiring and help young people find their way when otherwise they wouldn't. I think the American people, if they knew more about Job Corps, the support would be even stronger. But we put it at a very high priority, and we will continue to do so.

Mr. Ford. These young people at the Center, Mr. Chairman, if you don't mind, are deeply, deeply appreciative of the Federal efforts. They understand where the commitment comes from, the business community back home, particularly our computer service industry. We are the home to Federal Express Corporation, which creates the lion's share of the jobs in our local economy, and they have also helped to really create and spawn a new sort of job creation effort there in the Memphis area. With the continued support of this Center and some of the other efforts under way, hopefully the region will continue to grow and live down the fact that regrettably Dr. King was assassinated in my district some 30 years ago and many of the challenges that we face.

I thank you again, Mr. Chairman, and look forward to working with you on this issue.

Mr. Porter. Thank you, Congressman Ford.

That completes our morning's session. We will stand in recess until 2:00 p.m.

On the record, and let me retract the recess, I wanted to

say on the record that Representative Pete Stark of California talked to me informally on the last vote about the matters that he wanted to testify in respect to particularly HCFA, and the funding of ombudsman services for seniors when the choices in Medicare are offered, and we will receive his testimony in the record and appreciate his advocacy.

[The prepared statement of Congressman Pete Stark follows:]

[Pages 2134 - 2136--The official Committee record contains additional material here.]

Mr. Porter. Now we stand in recess until 2:00.

Thursday, April 30, 1998.

WITNESS

HON. GEORGE NETHERCUTT, JR., A REPRESENTATIVE IN CONGRESS FROM THE
STATE OF WASHINGTON

Mr. Porter. We continue our hearings on the fiscal year 1999 appropriations and hearing testimony of Members of Congress.

I am pleased to welcome George Nethercutt of Washington to testify on NIH and NIDDK.

Mr. Nethercutt. Thank you, Mr. Chairman and Mr. Stokes. I am delighted to be here and testify today and to express my support for biomedical research and translation funding at the National Institutes of Health and the Centers for Disease Control and Prevention.

I do have a prepared statement which I would ask to be entered into the record, and I will try to summarize it as best I can.

As the Chairman knows and Mr. Stokes knows, the incidence of serious diseases enters most of our lives at one time or another. It affects us no matter our political affiliation and race or gender.

I have had some personal tragedy in my life, relatives who have contracted serious disease. My dad died of lung cancer 20 years ago, and I have a daughter who is diabetic, and it touches all of us. That is why I have been so committed, Mr. Chairman, to seeing the greatest resources in our Nation for health care research.

The National Institutes of Health function effectively and have a mission of curing disease. The NIH research, the CDC activities are essential to finding cures and advancing better treatments for these serious diseases.

I was pleased to see last year that the final appropriations legislation increased NIDDK funding above that to NIH overall, even though it was smaller than we wish it could be, but we also got some assistance through the Balanced Budget Act for diabetes research and especially Native American diabetes research which I think will be very helpful.

Last night, I was in attendance at part of the hearing and operation of the diabetes working group, which convened here

again yesterday at NIH, and was encouraged by what I saw in the time that I was there. They met from early in the morning until late at night.

This subcommittee approved legislation that directed their formation and directed that working group to look at the cures, the best evidence of cures for diseases like diabetes-- specifically diabetes, and also collected great scientific minds from around the country to do just that.

I can report to you both that the committee working group was enthusiastic, tremendous brain power, great ideas not restricted by convention necessarily but really were free thinking and being imaginative how we can chart a course to cure diabetes.

Diabetes funding has been on a trend downward. I believe it is on a trend upward now because of the seriousness, and it affects so many institutes, I think eight or nine at least, and it also affects 16 million people in our country and countless others who die or are afflicted by the consequences of diabetes.

About 2 weeks ago, Mr. Chairman, I went out to NIH and had a very good meeting with Dr. Varmus; and I sat with the representatives of the institutes, in many cases directors of the various institutes at NIH and talked to them about their mission, some of the progress they are undertaking and achieving and talking with them about my support and the support in Congress for doubling the research funds over the next 5 years. I think it is a wonderful goal, and we ought to do it.

There is an issue that this subcommittee has faced before and would look at again, and that is the issue of who has ultimate responsibility for how the funding goes. While I understand the arguments against making it a political judgment, it is the Members of Congress who have to make the judgment and answer to the citizens about how much money we spend on various diseases, and so I think Congress has a very important role to play in that decision.

We don't want to micromanage these various agencies, but there is a role that we need to play to make clear to the NIH and other research entities that there are priorities in the country that need to be addressed, and so my statement speaks in more detail about that, but I want to summarize that we have a responsibility as Members of Congress to make sure that the money is spent wisely.

I am serving as co-chair of the caucus. We have 158 Members who have signed on, and we are delighted that it is such a force, and I think we need to really mobilize not only diabetes-interested Members of Congress but people with Multiple Sclerosis and Alzheimers and all of the other diseases out there to get on board this idea that we need to assist this great research effort at NIH.

Because I speak here today in support of diabetes, I can certainly verify the statistical information that is out there about how the disease directly causes 180,000 deaths a year and permanently 75,000 people are disabled because of diabetes. It costs us about \$37.1 billion from disability, diabetes does, and it is a leading cause of many problems in our health condition in the country.

So I will just close by saying, Mr. Chairman, Lou Holtz met with me and perhaps with the two of you earlier this year. His son has diabetes and he said, ``If enough people care, you can solve anything.''

This is true. We have a lot of people who care in the Congress, and I know the two of you do and this subcommittee does, and I would just urge that additional funding be dedicated to diabetes and we move toward increased funding for NIH overall, and I thank you both for your attention today.

Mr. Porter. George, thank you for your very good statement.

[The prepared statement of Congressman George Nethercutt, Jr., follows:]

[Pages 2139 - 2141--The official Committee record contains additional material here.]

Mr. Porter. I know that you know that we will do everything that we can to respond to it positively and that we share your concern that we need to strongly encourage NIH to put more resources into diseases that effect people more broadly. As you and I have discussed, we are doing that.

We think that the allocations previously were justified under circumstances that existed previously, but we think that circumstances have now changed and that there is no question that we need more money for research into diabetes and cancer and heart disease and others, that perhaps because of the AIDS epidemic and the lack of knowledge at the beginning and for some time as to how it would effect broad populations prevented us from doing that.

Now, I think, we need to move back to where we would have been and to try to make up some of that lost ground, and we can do that best by substantially increasing the money that we put into NIH and then encouraging that money be put into research and diseases like the ones that we have been discussing.

Mr. Stokes.

Mr. Stokes. Thank you, Mr. Chairman.

I would just like to take a moment and commend Mr. Nethercutt for his testimony here today. He has appeared before us on other occasions, and you have always been an ardent advocate on behalf of the diseases. I quite agree with you that diabetes is one of the most devastating diseases that one can incur.

You mentioned the fact that most families have some type of experience with it, and I have a brother who passed 2 years ago. Although he incurred cancer later, he also had diabetes, and so I am familiar with the devastation this particular disease brings upon those it afflicts.

I appreciate so much your testimony today.

Mr. Nethercutt. Thank you.

Mr. Porter. You have been a real leader, and your leadership on the task force has been appreciated, and we want to work closely with you to see if we can't all do a better job of directing and providing resources to NIH.

Mr. Nethercutt. Thank you very much.

Mr. Porter. We have no other Members here. We are about to

have a vote, and we will stand in recess until after the vote.
[Recess.]

Thursday, April 30, 1998.

WITNESS

HON. TIM ROEMER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF INDIANA

Mr. Porter. The subcommittee hearing will come to order, and we will continue the testimony from Members of Congress, and in the order specified, we are pleased to welcome Congressman Tim Roemer to testify regarding the Close-Up Foundation.

Mr. Roemer. Thank you, Mr. Chairman.

I would, first of all, ask unanimous consent to revise and extend and have my entire statement be entered into the record.

Mr. Porter. Without objection.

Mr. Roemer. Thank you, Mr. Chairman.

First of all, I would like to thank you and your staff and the other members of the committee for all the hard work you do and the hard decisions that you face on this committee. You have very, very many tough choices and important programs to try to fund, and you listen to the different testimony by Members of Congress all day, and we appreciate your understanding and your sensitivity and your difficult decision-making process.

Thank you again for your invaluable work you and the subcommittee members such as Mr. Stokes make on a daily basis.

I want to start off by recommending, Mr. Chairman and Mr. Stokes, the full level of funding for the Close Up program. My statement has been entered into the record so I want to say, and hopefully in an eloquent way, how important this program is for those underserved and at-risk young students to get them involved in understanding government and eventually participating in civil responsibility.

We find out more and more every single year about the capability of young people. We find out that now two and three years old might be the best time for them to learn a foreign language.

We understand in science in order to get young children interested in becoming a scientist, you have to capture them at the third and fourth grade level. In order to play T-ball, we are now starting them, and I am a coach, at five years old.

In order to get them involved in music, the governor of Georgia is handing out tapes of Mozart to parents to play music for young people to increase their linear thinking.

We are finding out how important it is to get this early learning going, yet in education for civic responsibility and political participation which the Close-Up Foundation encourages, we are not doing as much as we might be able to.

This program is one of the few in the country that achieves the objective of getting people involved by bringing them to Washington, D.C., targeting underserved populations and at-risk populations, exposing them to Capitol Hill, showing them the good things that happen up here and then seeing them get

involved later on in their lives.

UCLA sponsored a study earlier this year that shows that only 26 percent of the freshman class thought that government was relevant to their lives, the lowest figures I believe since the study has been done.

Now that shows that we are not starting early enough and getting our young people involved in the political process, and this is a non-bipartisan way that leverages private dollars that concentrates on the most at-risk population and one that I think has done some great service for our community and country in the past, and I would strongly encourage you to consider full funding of the program, and I thank you for your time.

Mr. Porter. Tim, thank you very much for your testimony.

[The prepared statement of Congressman Tim Roemer follows:]

[Pages 2144 - 2146--The official Committee record contains additional material here.]

Mr. Porter. Don Young was in this morning to iterate the words that you said about Close-Up, and obviously there is very strong bipartisan support for a program that really touches all of us, and we hope we influence the young people that come to visit us as well.

Thank you for your testimony this afternoon.

Mr. Roemer. Thank you.

Mr. Porter. Mr. Stokes.

Mr. Stokes. I just wanted to commend Tim for his testimony here on behalf of Close-Up. I happen to think it is one of the finest programs that I have had the chance to participate in. Oftentimes now, I have a young person who is a professional, lawyer, doctor, some other professional, and they come up and say, the first time I met you was when I came to Washington with the Close-Up Foundation, and they still recall the Close-Up program which put them in touch with Washington the first time, and it is an excellent program.

Mr. Roemer. We will miss you, Mr. Stokes, when you go back to private life in Ohio, and I am sure that the Close-Up people will, too.

Thank you, Mr. Chairman.

Thursday, April 30, 1998.

WITNESS

HON. DARLENE HOOLEY, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF OREGON

Mr. Porter. Just to inform the Members who are here to testify, we are going to go through the list as the time slots are set, and any Member who is not here at the time will then drop down in the order and have to testify later.

Next will be Congresswoman Darlene Hooley. She is testifying on certain projects.

Ms. Hooley. Mr. Chairman, thank you very much for letting

me have the opportunity to testify today.

I am here to respectfully request inclusion of several projects that are administered by the Departments of Health, Education and Human Services.

The first is a program called Distance Education Alliance. What it will do is link all of Oregon's higher education institutions into that partnership that will establish a degree program using existing distance technologies. Oregon is a rather rural state--and it will allow access to education for an advanced degree for individuals so they can have the ability to have access to education.

What this program is about, this Alliance, is they want to develop about 200 courses for delivery in this distant education mode. I am seeking \$3 million to implement the program. This would be under the President's Learning Anywhere Any Time Program, and the purpose would be to support the faculty training, the course development and technology expenses to make those degree programs possible.

I am also seeking support for a program at Western State University, a Spanish Language Training Institute. The purpose is to offer intensive language courses to civil service and judicial personnel.

This university is located in the middle of an area that has a lot of Hispanics and Latinos. This program would help communities in the Willamette Valley overcome significant language barriers by ensuring that our civil service and judicial personnel have the communication skills to provide those services. I am requesting \$350,000 to help establish the institute, and hopefully this could be part of the Professional Development Program under the Bilingual and Immigrant Education Program.

The next thing I am looking at, is an initiative to help forge partnerships between institutions and smoothing the seams for students between educational levels.

So those students going into community colleges or colleges and those going from community colleges to higher education, it is a way to improve their transition so it is seamless. The program works to provide strong support services, develop cross-institutional faculty and student services to help ease those transitions of students between educational levels.

We have institutions already working on this, and I am requesting \$750,000 for a pilot program to enable the expansion of the partnership. Again, we would be happy, once we go through this pilot project, to make sure that we spread that information throughout the United States.

Another program that we are asking funding for is the Environmental Health Science Education Program at Oregon State University. It focuses on increasing the public's ability to understand and make informed decisions on environmental factors contributing to health and diseases. I am requesting \$300,000 for this program.

Finally, I am joining the entire Oregon congressional delegation to request money for a one-time grant of \$3 million to help build a Women's Health Center in Portland, Oregon.

This facility is for the entire State. It would be a distribution point for patient education materials, serve as a conduit for public education. It would be an asset to our

community to improve women's health, and I urge this committee to support its construction. There are lots of partners, and we are hoping that the Federal Government can also be a partner.

Thank you for the opportunity to testify, and you have my full written testimony.

Mr. Porter. Thank you, Congresswoman Hooley. We will consider your requests.

Ms. Hooley. Thank you.

[The prepared statement of Congresswoman Darlene Hooley follows:]

[Pages 2149 - 2151--The official Committee record contains additional material here.]

Thursday, April 30, 1998.

WITNESS

HON. JAMES L. OBERSTAR, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MINNESOTA

Mr. Porter. I am not going to comment on the testimony because it slows things down, and we are so far behind because of the votes. I will just call on each Member and listen.

Representative Jim Oberstar, testifying on breast cancer, energy assistance, library services, rural health programs and adoption opportunities. Jim, nice to see you.

Mr. Oberstar. Thank you very much. You just about gave my testimony right there.

You have been very kind and thoughtful for so many years on the subcommittee as I come here in memory of my late wife Jo to talk about the need for breast cancer research funds and this committee has responded to the challenge.

When Jo first self-diagnosed by accident her breast cancer, there was only about \$35 million for research funding in NIH for that little-known, little-understood area of public health. In the 8 years that she coped with breast cancer treatment, surgery, radiation, chemotherapy and hormone treatments, 300,000 women died of the disease, and it finally claimed her life.

We have three daughters, and as each one turned 21, knowing that there was the history of breast cancer in her family, her mother had it, she died of it, each of those girls has gone to have a base-line mammogram. Mammograms weren't even available when Jo was diagnosed.

That old adage, you can't throw money at problems, if you don't have money, you can't address the problems, and the level of \$500 million of funding for breast cancer is a reasonable level to request. This is not throwing money at problems. This is engaging the best minds of America to approach the issue from its multi-dimensional aspects, to look at it, each researcher, from a different aspect.

I have spent days at NIH at different times going through their laboratory and their programs, the research protocols, and at other research centers across the country doing the same, and I know that it is going to be a continuing, long

struggle. We are getting closer.

As Dr. Steve Rosenberg, chief of surgery at the National Cancer Institute said, we have begun to make a wedge in the bleak stone face of cancer. Our task now is to widen that crack, and this is funding to do it.

The Women's Health Initiative that is looking at a broad range of women's health concerns, funding at the \$200 million level I think would be the largest research initiative on women anywhere in the world.

The early detection program for Centers for Disease Control, I appeal to the committee to give it the funding that it requires.

Energy assistance, we had a mild winter, but we in the Northern tier States, Mr. Stokes included, know that every year the glacier makes a comeback, starting in November in my part of the country. While the level of funding is in the range of a billion dollars, 10 years ago we had \$2 billion funding for LIHEAP.

The needs of elderly and low-income families have not diminished or gone away again. They haven't benefited from this great economic recovery we have had, and I know families who have been saved by the funding.

I also appeal for continuing your--at least for this year, the disproportionate share payments for Minnesota hospitals which were affected by a reporting error in the 1997 balanced budget agreement. You addressed that issue last year. The State needs this one additional year of transition to address the problem, and I think the reporting error issue will then be resolved.

The Community Health Centers Section 330 Program Grants, I just cite because I was there recently on the northern tip of Lake Superior, Minnesota, Grand Marais, a small community of 1,250 people, it is 76 miles to the nearest health facility along a two-lane road, 110 miles to the next hospital.

Without the Community Health Centers grant program, those people would be without health care, and communities die when they don't have it. It has made all the difference in the world to this little community who is totally dependent on the health facilities at that one place.

And, finally, do continue the Impact Aid program. It is vitally important to the small towns in my district, like the county in which Grand Marais is located, it is 96 percent public ownership, most of it Federal. Without the Impact Aid, they can't provide the services that the communities need. They don't have the tax dollars. Four percent of the land is private ownership. Without the aid that you provide through this program, they don't have libraries. They don't have all of the other public facilities.

I know that my time has expired, and I appreciate your consideration.

Mr. Porter. Jim, thank you very much for your testimony.

[The prepared statement of James Oberstar follows:]

Mr. Porter. The one that you mentioned that is a problem is the disproportionate share because last year we realized that this was a problem, but we felt that we could only address it on a one-year basis and that the authorizers have to correct the problem.

Mr. Oberstar. That is fair enough.

Mr. Porter. We will keep an open mind on it, but that one may be a problem.

Mr. Oberstar. I understand, and I can appreciate that.

Thursday, April 30, 1998.

WITNESS

HON. ELIJAH CUMMINGS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MARYLAND

Mr. Porter. Congressman Cummings of Maryland to testify on Healthy Start.

Mr. Cummings. Thank you, Mr. Chairman.

I have only one issue, a very important issue, Mr. Chairman, and I have introduced H.R. 3724, the Healthy Start initiative continuation, which would establish a permanent authorization for this program.

In my district, Baltimore, Healthy Start has been extremely effective. So often when I visit elementary schools and I see little children who unfortunately were damaged in the womb, they are starting 30 feet behind the starting line of life. It really does concern me greatly.

In our district, Healthy Start has succeeded in reducing Baltimore's infant mortality rate. The pre-Healthy Start baseline infant mortality rate of 20.1 infant deaths per 1,000 live births in a Healthy Start project area was reduced to 13 by the end of 1995, a 35 percent reduction.

Healthy Start also assisted Baltimore City in preventing instances of very low birth weight babies. According to the Johns Hopkins University School of Hygiene and Public Health, Healthy Start has lowered the incidence of low birth weight babies by nearly 67 percent.

I believe that all of us in this Congress and most Americans believe that--they don't mind being taxed, but they want to make sure that we spend their dollars wisely and that we are efficient and cost-effective. When you think about the cost of a low birth weight baby, trying to bring that baby up compared with the money that we are spending compared with Healthy Start, there is no comparison. That doesn't even go into saving the pain and the anguish that these children go through.

In the City of Baltimore, about 35 percent of the women enrolled in Healthy Start have problems with drugs and alcohol. The evaluation data suggested Healthy Start is just as effective in women who abuse controlled substances as compared to women who do not.

On September 27, 1997, the Secretary of Health, Donna Shalala, when announcing the new Healthy Start grants totaling nearly \$50 million to 40 new communities with high infant

mortality rates, stated and I quote, ``The five-year Healthy Start Initiative has demonstrated what works. The best way to make sure that babies are healthier is for all pregnant women to get early prenatal care, adequate housing, and support from family and friends.''

Mr. Chairman, I also want to applaud you and Mr. Stokes and other members of the committee for having a concern about this very important initiative. I understand that we have a commitment to the American taxpayer to effectively use those tax revenues that they entrust to us. The Healthy Start program has proved to be a success. It saves lives and makes for a healthy beginning into parenthood for both low income women and infants, and so I ask that you take into consideration this legislation, because, again, I think that it has been effective. It is one of the many things that we can point to from a bipartisan standpoint that this Congress has done to really make a major difference in the lives of children and parents.

Thank you.

Mr. Porter. Congressman Cummings, thank you for your good testimony.

[The prepared statement of Congressman Elijah Cummings follows:]

[Pages 2161 - 2165--The official Committee record contains additional material here.]

Mr. Stokes. This testimony, Mr. Chairman, is so important because, through this particular program, we have been able to see a reduction in the infant mortality rate, particularly in the Northern communities and all of the inner cities in which the program was originally established. This is one program which has been effective in terms of making a difference, and we appreciate your testimony.

Mr. Porter. Thank you very much.

Thursday, April 30, 1998.

WITNESS

HON. CARLOS A. ROMERO-BARCELO, A REPRESENTATIVE IN CONGRESS FROM THE COMMONWEALTH OF PUERTO RICO

Mr. Porter. Carlos Romero-Barcelo of Puerto Rico, testifying on the Frank Tejeda Scholarship Program.

Mr. Romero-Barcelo. Thank you, Mr. Chairman and Mr. Stokes. I appreciate the opportunity to testify before you today.

I am appearing to discuss the Frank Tejeda Scholarship Program. I am requesting that the committee provide \$5 million for fiscal year 1999 for this important program.

This March, the House Committee on Education and the Workforce voted to establish the Frank Tejeda Scholarship Program in the Higher Education Act. The Frank Tejeda Scholarship Program honors the memory of our former colleague, Frank Tejeda, who died last year while serving the 28th

District of Texas. As a national leader and role model to the Nation's students, it is fitting that this program carry his name.

Under the Frank Tejeda Scholarship Program, scholarships of \$5,000 per academic year for up to 4 years would be awarded to students who are proficient in Spanish and English and who want to be teachers in our Nation's public schools. The award recipients must agree to teach in public schools that have a need for teachers and other professionals and others who are proficient in Spanish. This is directed to providing the schools the opportunity to have teachers who understand the language of those students who are being taught English. Sometimes they are teaching to a student who doesn't know English. A teacher who doesn't know Spanish would have a difficult time teaching Spanish students.

Also, a teacher proficient in Spanish would provide the ability for those students who have difficulty communicating in English with a counselor in school so we don't have children leaving school at an early age.

Congressman Frank Tejeda was a person of tremendous courage and conviction. Like too many Hispanic youth today, he dropped out of school, but he persevered. At the age of 17, he volunteered for the Marine Corps and served a tour of duty in Vietnam. For his courage in battle, he received the Bronze Star. While in the military, he received the highest grades ever in the Marine Corps Officer Candidate School.

When he returned to the U.S., he returned to San Antonio and graduated from St. Mary's University with a bachelor of arts degree. Congressman Tejeda then went on to receive a law degree from the University of California at Berkeley, a master's degree from Harvard and an LLM from Yale.

The Frank Tejeda Scholarship Program embodies the academic excellence that Frank Tejeda pursued throughout his life and his commitment to helping others achieve their personal and professional goals.

Under the Frank Tejeda Scholarship Program, funds would be awarded to students who are low-income or eligible for a Pell Grant; U.S. citizens; enrolled or accepted for admission, full or part-time, at a graduate or undergraduate level at an institution of higher education that has an accredited teacher preparation program; and can demonstrate English and Spanish proficiency. The Tejeda scholars would be students who have demonstrated outstanding academic achievement.

From the sums appropriated for this program, the Secretary of Education would allocate to each State an amount equal to \$5,000 multiplied by the number of scholarships determined by the Secretary to be available to such State, which shall bear the same ratio to the number of scholarships made available to all States as the State's population ages 5 through 17 bears to the population ages 5 through 17 in all States, except that not less than 10 scholarships shall be made available to any State.

For Hispanic Americans, it is imperative that bold steps be taken now to bridge the educational and economic gaps that separate Hispanics from the rest of the Nation. Undoubtedly, staying in school is a key to helping to improve the quality of life for Hispanic Americans. There is an urgent need to educate and train persons at the college level who are willing to go

into urban and rural settings that are in need of teachers who are proficient in both Spanish and English. For all these reasons, the Frank Tejeda Scholarship Program is supported by the Congressional Hispanic Caucus.

Hispanics now are the fastest-growing population in the Nation and by early in the 21st century will be the largest minority population in the United States. The number of Hispanic school age children is growing rapidly as well. In 1980, more than 4 million Hispanic children between the ages of 5 and 17 were enrolled in the Nation's public schools. By the year 2005, this population is expected to double.

How this population of students fares in the Nation's schools will have great national implications in the 21st century and beyond. The Hispanic student dropout rate, the highest of any group in the Nation, is a matter of great national concern. The availability of well-qualified teachers who can serve the needs of this student population can make a tremendous and positive impact on the lives of these children and play a significant role in keeping them in school.

Thank you, Mr. Chairman.

Mr. Porter. Thank you, Mr. Romero-Barcelo.

Is this program authorized by the Higher Education Act we are considering right now?

Mr. Romero-Barcelo. Yes. It is on the floor right now.

Mr. Porter. Thank you very much for your good testimony.

Mr. Romero-Barcelo. Thank you very much.

[The prepared statement of Congressman Carlos Romero-Barcelo follows:]

[Pages 2169 - 2171--The official Committee record contains additional material here.]

Thursday, April 30, 1998.

WITNESS

HON. BERNARD SANDERS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF VERMONT

Mr. Porter. Arriving just in time, Congressman Bernie Sanders of Vermont, testifying regarding the Social Security Administration; and it looks like you brought a significant entourage that you should introduce.

Mr. Sanders. These are young people from the State of Vermont. We have about five separate schools here today, and I would like to introduce the young people to Chairman Porter and Mr. Stokes and Congresswoman Pelosi from California.

Mr. Porter. We welcome each one of you.

Mr. Sanders. Thank you very much, Mr. Chairman.

Mr. Chairman, let me put my discussion into context, and the context regarding senior citizens is that, in my view, in the last few years the United States Congress has largely not been friendly to senior citizens if you look at the \$115 million cut in Medicare that was passed last year; and the implications are now being seen in Vermont, cuts in home health care, and in veterans' care and we are seeing that in VA

hospitals around the country; if we look at the consistent attacks, and I think your committee has been strong in resisting that, but attacks to cut back on LIHEAP, for example; if we look at what is going on in senior citizen housing and the fact that we are not building senior citizen housing despite the enormous backlog and waiting lists; if you look at an issue that has not been getting the attention that it deserves in that the Bureau of Labor Statistics is reconfiguring, if you like, what inflation is, and their work has resulted in a 0.7 percent reconfiguration lowering for Social Security.

Add all of those things together, I think we have not been treating seniors well, 50 percent of whom have incomes of less than \$15,000 a year.

Now, having said that, it seems to me that no matter what our political point of view, we should appreciate that the Conduit Meal Program is a fantastic program. Not only is it the humane and right thing to do, but it is cost-effective.

Conduit Meal Program deals with two issues. Number one, seniors come together for meals. Now, in Vermont, we have centers to provide meals one day a week, sometimes five days a week. What is important is not only that seniors get nutrition, good meals, but social workers see them and directors. They can say, you are not feeling well, Mr. Jones; go to the doctor.

So the Conduit Meal Program is very important. It allows seniors to socialize, and I think we can make the argument that it is cost-effective. We gain more than we lose.

Obviously, I don't have to tell you very much about the importance of the Meals-on-Wheels program. What kind of country are we if we are not taking care of low-income senior citizens who do not get enough food, who do not see people and live in isolation?

I would argue that, given the cuts that have taken place to various senior citizen programs, that, no matter what our political persuasions may be, I think it is appropriate to say that in America we are going to substantially increase funding for the Conduit Meal Program. I think it is a very good investment. If we understand that we are talking about a program which, combined, probably is 5 percent of one B-2 bomber, I think it is a good investment; and I would hope that you would stand up for America right now and say, look, we are not going to ignore the seniors any more. That is issue number one.

The second point that I would like, and with your permission, Mr. Chairman, I will give you my written remarks for the record, deals with the administration of Social Security, and we are not talking about the Social Security but the administration of.

My reaction is that, last year, there was in the Balanced Budget Agreement, my recollection is that there was--what would amount to a 23 percent cut in the administration for Social Security.

My concern there is we will agree or not agree with what is going to happen with Social Security, but I get a real concern when folks in my office and perhaps in your office, a constituent calls and they have a problem with Social Security. Your caseworker gets on the phone, and it is going to take

quite a while to get a response, and that is from a congressional office. What happens when Mrs. Jones herself says, I have a question about Social Security?

I think the evidence is pretty clear that, right now, we are not doing a good enough job in terms of having the personnel out there to respond quickly. That is not a secret. It is not just Vermont that has that problem. Why then are we cutting back substantially on the administration of Social Security?

I hope very much that this is not just a back doorway to make people feel less kindly toward Social Security. I would hope that is not the case. But it seems to me if anybody has a concern about Social Security, they should be able to get a prompt and accurate response from a qualified Social Security employee.

So those are my two concerns, Mr. Chairman; and I thank you very much for hearing me out.

[The prepared statement of Congressman Bernie Sanders follows:]

[Pages 2174 - 2175--The official Committee record contains additional material here.]

Mr. Porter. Congressman Sanders, I think you will find that we have not cut back on the administration of Social Security. We consider it just as high a priority as you do. In fact, we have been providing Social Security with substantial increases for the computers that they need to do their job better.

So, in any case, we do hear what you are saying very clearly; and we agree with you that it is a very high priority that people get served very promptly and efficiently by the Social Security.

Mr. Sanders. My understanding is that, according to an analysis by minority staff, and I don't know if Ms. Pelosi and Mr. Stokes want to comment about this, but the freeze, the 2002 freeze reflected in last year's budget for discretionary funds for Social Security would result in a cut baseline of 23 percent.

Mr. Porter. The staff tells me that it was in the budget agreement, but we didn't follow the budget agreement.

Mr. Sanders. I am glad to hear that. So, in fact, it is a cut that did not take place?

Mr. Porter. That is correct.

Mr. Sanders. That is a wise decision.

Mr. Porter. It is a high priority.

Mr. Sanders. In terms of the Conduit Meal Program, I think it is a cost effective and important program.

Mr. Porter. Thank you, Congressman Sanders, for testifying today. We definitely will take your testimony into account and will be marking up as soon as we get a budget resolution which may be sometime soon and may not be. Thank you very much.

Mr. Sanders. Thank you very much, Mr. Chairman.

This is 38 percent of our entire State's population.

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Thursday, April 30, 1998.

WITNESSES

HON. GLENN POSHARD, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF ILLINOIS

HON. JIM NUSSLE, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF IOWA

Mr. Porter. I want to ask the Members who have been waiting very, very patiently, one of our Members has informed us that she has a very serious time problem, and she has the demonstration that she wants to show on the monitors that have been set up here and that they have to complete that and be finished by 4:00.

Therefore, with your permission, I would like to take Juanita Millender-McDonald--she is not here in the room?

I am sorry, I just assumed that she was in the room. Okay, she is not in the room. Let me take that all back.

Congressman Glenn Poshard of Illinois and Congressman Jim Nussle on the Rural Health Care Coalition. Thank you for your patience.

Mr. Nussle. Thank you, Mr. Chairman, for allowing us to come here and testify on the Rural Health Care Coalition.

I want to thank my friend Glenn Poshard who has been my co-chairman in this endeavor. I know that he is looking for another endeavor these days, but I want to tell you that he has been a true friend to rural health care issues during his tenure here in Congress, and, regardless of outcomes, we will be very sorry to lose his leadership on that coalition.

I know that you know that, Mr. Chairman, coming from the same State, but I just wanted to say that, Glenn, it has been a real pleasure working with you.

Mr. Chairman, we have 140 members of the Rural Health Care Coalition, and we want to thank you for your leadership and the committee's leadership. In the past year, you have been very supportive of our issues and have demonstrated that in the priorities that you have placed in the appropriations bill.

By the way, most of our requests are continuing requests; and certainly they come with additional dollars. We believe that they could be heightened, but I am sure that is true with a number of different programs and entities that come to you around the table. But we did want to highlight that for you and give that to you in written form, which we have done.

Just to put it in context, and I thought it was kind of interesting, I read a news story not too long ago about a suburb in New Jersey--and this is not to be disparaging towards New Jersey; this could happen anywhere--but there is a major controversy going on involving an ambulance that took 11 minutes to arrive at the scene of an accident, of a call, and it was a major controversy that it took so long, 11 minutes, and what I found interesting about that controversy is that is health care delivery in urban and suburban areas.

In rural areas, as you know, Mr. Chairman, 11 minutes would be a Godsend. If you have a tractor roll over on top of you during planting season or you have a heart attack in your home in Ryan, Iowa, and you have to get up to Manchester, Iowa, that would be an 11-minute trip one way for the ambulance, let alone

the return trip to get you to the emergency room, and that is why rural health care is so important.

We need different answers and solutions, and that is why the programs that we advocate are for flexibility and for new ideas and for grants to test new theories and new deliveries.

One that is in the budget that I want to highlight, because the rest are continuing requests, is called the Medicare Rural Hospital Flexibility Program, which was part of the Balanced Budget Act of 1997, and it is intended to recognize that there are hospitals in rural areas that are not going to look like or be like hospitals in suburban or urban areas. They are just not going to possibly be able to provide the same kind of services and yet the emergency basis of those clinics, of those hospitals need to be there for the clients and for the citizens that they serve.

So, basically, what we are trying to do is improve the access to this essential health care service through critical access hospitals and rural health care networks; and this program through Medicare would allow us to do just that.

With that, let me just yield my time, whatever is left, to my friend, and you know this issue very well. I thank you for your support and your patience, and I will let Glenn finish off.

[The prepared statement of Congressman Jim Nussle follows:]

[Pages 2178 - 2179--The official Committee record contains additional material here.]

Mr. Poshard. I appreciate that, Jim; and, Mr. Chairman, let me thank you and other members of the committee for being very sensitive to the Rural Health Care Caucus over the years. We are very appreciative of it.

Just to mention a few things here. The National Health Service Corps. As you know, it is very difficult for us to recruit doctors into the underserved areas of this Nation. The ability for us to help doctors get through medical schools and then relocate in these medically underserved areas is very, very critical; and we want to continue as much funding as we possibly can in that area.

The new designation that we came up last year in the budget which you supported, the Rural Critical Care Hospital, we all know that it is not possible for a rural hospital that has 40 beds and maintaining an inpatient service, it is not possible for them to exist much longer; and the new critical care status allows reimbursement primarily for emergency room care and outpatient, which is what is going to be essential for keeping our hospitals in the small rural communities at least open to the capacity that we can continue to provide adequate services for them. That is real important.

I want to just mention one other thing in the time that we have remaining. This is not part of the Rural Health Care Caucus program, but I serve a large coal mining district, and my father's generation just saw thousands of young people go down into the mines and come up when they were 35 years old with black lung disease and be dead before they were 40-45

years old. The black lung clinics that you folks fund in the coal-producing States around the Nation are so important.

Black lung is a respiratory disease that coal miners get which is worse than anything that you can possibly imagine; and if you ever visited these clinics and saw these people barely having the capability to stay alive, you would know how important they are. So if we can maintain that \$5 million funding for those clinics, it is a huge, huge issue in some poor regions of the State that are all rural. It is not in Caucus bills, but it is real important to me and the coal mining areas of the country, and I want to implore you not to cut any of those funds if you can keep from doing it at all.

[The prepared statement of Congressmen Glenn Poshard and Jim Nussle follows:]

[Pages 2181 - 2184--The official Committee record contains additional material here.]

Mr. Porter. Let me thank both of you for your testimony, and again we will do the best that we possibly can in each of those areas.

Let me say, Glenn, you have been, as Jim said, a tremendous advocate for rural health programs; and I am going to get a chance to say this many more times, but we are going to miss you around here.

Mr. Poshard. Thank you. I appreciate that.

Mr. Nussle. Thank you, Mr. Chairman.

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Thursday, April 30, 1998.

WITNESS

HON. JUANITA MILLENDER-McDONALD, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mr. Porter. Now Representative Millender-McDonald is here. We are going to put you on ahead of time alone, and you have a video that you want to show us.

Ms. Millender-McDonald. That is right.

Mr. Porter. Please proceed any way you want.

Ms. Millender-McDonald. Mr. Chairman, thank you very much, and to the ranking member and all the committee members, I want to thank you for this opportunity to join me today to discuss how telemedicine can improve the accessibility and quality of health care provided to numerous Americans.

Telemedicine improves health care to patients by shortening the time between diagnosis and treatment, lowers cost for treatment by detecting conditions before they become serious or lead to emergency room visits, and expands opportunity for continuing education for health care providers. It can be used in home health care to monitor medications, blood pressure, and for more serious conditions such as diabetes, which causes blindness, kidney failure and amputations among far too many African-Americans today.

Telemedicine can also be used to educate and care for the underserved communities in the areas of pediatrics, prenatal care, cardiology, depression and dermatology.

In addition to the immediate health benefits and long-term financial savings that are natural outcomes of this medical care, telemedicine creates jobs. The telemedicine sites can provide jobs for those who are moving from welfare to work through technical training and the use of telemedicine equipment. In fact, a telemedicine site that is run by Drew University in my district has done just that.

I have Dr. Charles Flowers, who is the founder of the first-ever urban telemedicine site in the country, who is joined by two women who have made the very successful transition from welfare to meaningful, self-sustaining and rewarding employment. This was launched in 1996.

The Drew University and the Community Development Commission County of Los Angeles' telemedicine site is focused on providing preventive eye care and treating serious eye conditions. It is located in a public housing unit and has already served hundreds of patients, the majority of whom made their first visit for an ophthalmologic examination at this site. Dr. Flowers and his colleagues at Drew University have diagnosed hypertension retinopathy, cataracts and preventable blindness caused by HIV, which continues to be the number one killer of African-American women aged 25 to 44.

I would like to have Dr. Flowers demonstrate how this urban telemedicine project works.

Dr. Flowers.

[Telemedicine demonstration.]

Ms. Millender-McDonald. As you can see, the telemedicine site, as with many others throughout the country, provides the medical attention that is not only equivalent to, but oftentimes better than a regular physician's visit. By taking a picture of the eye, Dr. Flowers or any other doctor has a visual image of the eye that is saved on a regular personal computer that can be used in the future for follow-up treatment or additional diagnosis. This is a clear benefit over doctors relying on their memory and their notes.

This urban telemedicine site helped numerous people in and near my district, while this project has provided a critical service, as Dr. Flowers noted. Telemedicine, and urban telemedicine in particular, improves the rate of early diagnosis, enhances disease surveillance and closes the gap between the poor, underserved and predominantly minority communities that are continually denied access to health care or are provided with less-than-adequate health care.

I want to thank you, Mr. Chairman, and the ranking member. I know that you are committed to improving this Nation's health care in the most cost-effective way. I hope after today's telemedicine demonstration you are as compelled as I am to ensure that we provide the necessary funding for both rural and urban telemedicine for those most in need.

Thank you very much.

[The prepared statement of Congresswoman Juanita Millender-McDonald follows:]

Mr. Porter. I can tell you right now, Congresswoman Millender-McDonald, that we are just as impressed as you are with the technology, and its application fits right in--we just had the Rural Health Care Coalition, Jim Nussle and Glenn Poshard, and it fits right in with what their needs are as well.

Ms. Millender-McDonald. Thank you. We have worked very well with the rural community, and so thank you very much for this opportunity to come before you.

Mr. Porter. Thank you.

Mr. Stokes.

Mr. Stokes. I just want to associate myself with your remarks and concur. I want to compliment you on your statement and how impressive the presentation is and how much it ties into our work.

Ms. Millender-McDonald. Thank you.

Mr. Porter. Thank you, Mr. Stokes.

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Thursday, April 30, 1998.

WITNESSES

HON. RANDY ``DUKE'' CUNNINGHAM, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

HON. CHET EDWARDS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS

Mr. Porter. The Impact Aid Coalition, represented by Congressman Duke Cunningham and Chet Edwards.

Mr. Edwards. Duke had to leave because of another meeting, Mr. Chairman.

Mr. Chairman, I will be very brief because I know that time is limited.

Two things I would like to say in addition to submitting Mr. Cunningham's and my testimony.

First, I wish any cynic about Federal programs would have sat here as I did through the last number of witnesses talking about black lung clinics, Healthy Start programs and medical and breast cancer research at NIH. I have great respect for the work of this committee, although I do not envy you in having to weigh these incredibly difficult priorities.

Quite frankly, I was one of those voting against the highway bill because I was afraid that, ultimately, it would take money away from the incredibly important programs that you are supporting.

The second thing I want to say to you, Mr. Stokes, is thank you for your leadership on the Impact Aid program. Mr. Chairman, you have especially gone the extra mile to speak for those who otherwise wouldn't have a voice, and of all of the deserving groups in America I can think of few more deserving than the children of military families.

I am going to catch the first plane home so I can be with my children, because I hate being away from them for 3 days and

2 nights, but yet, in just a few weeks, I am going to have to see 2,000 to 3,000 parents off in Fort Hood in my district who will be serving their country at the President's request in Bosnia for the next 6 months, and I can't imagine leaving my 9-month-old baby now and coming back when he is nearly a year and a half.

I don't think that we can put a dollar value on the kind of sacrifice those military children make; and, as both of you know, because of cuts in the defense budget, military families are spending more time away from their families today than they did a year ago or 2 years or 3 years ago.

The final point I would say is, considering the number of Native American children served by this program and the fact that one-third of our military families are minorities, the Impact Aid program is not only good for helping military children, Native American children and minority children and improving the ability to bring the best and brightest in our military, this program is truly one of the largest minority education programs in America--regardless of race or background. I can think of few groups more deserving than those who make the sacrifices of our military children.

For those reasons, I would urge you for full support of the requested budget this year. Most importantly, I want to say thank you. The program would not be where it is today had it not been for your help and the work of this committee.

[The prepared statement of Congressmen Randy ``Duke'' Cunningham and Chet Edwards follows:]

[Pages 2191 - 2193--The official Committee record contains additional material here.]

Mr. Porter. Chet, I very much appreciate your testimony and also your tremendous advocacy on behalf of Impact Aid which has been constant throughout all of the time that we have been in Congress.

I wish that the President had done a little bit better job for us because it makes--even though we will tell you we don't listen very much to the President's numbers, it makes it more difficult for us to get to the kind of position where we want to be in the absence of strong support from the White House.

Mr. Edwards. I would like to find, with your help, Mr. Chairman, the person down in the bowels of the OMB office that each year zeros out Part B Impact Aid. It has happened for years now, but I understand your comment.

Mr. Porter. We will do the best that we absolutely can on this.

Mr. Edwards. Thank you. You always have.

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WITNESS

HON. NANCY JOHNSON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CONNECTICUT

Mr. Porter. There is a second bell already rung. We are going to have to stand in recess.

Mrs. Johnson. Can I just make my presentation? I am going to have trouble coming back.

Mr. Porter. Sure. Congresswoman Nancy Johnson.

Mrs. Johnson. I think I can do this in 2 minutes. Thank you very much.

Other members of the Caucus will testify when you reconvene, at least I suppose that they will, but I want to go through, quickly, a few things. I will just enumerate them and leave my longer testimony.

I have testified before you many times in support of Title X funding being. I feel as strongly about Title X funding as I ever have. There are more and more low income women depending on these clinics for their primary health care. Likewise with the Community Health Center program. That is just critical to the well-being of our inner city families.

The Office of Women's Health has done an enormous amount to reach out and develop national centers of excellence, women's health information centers, improve the quality of mammograms, and is about to launch a national osteoporosis education campaign, a totally preventable disease with sufficient education.

I want to mention two other things.

NIH funding. I know how you are committed to NIH funding. I have a little bill that needs attention, and we hope to get it through the Congress this year. Because, as we increase NIH funding, we must also provide better support for clinical research because the managed care competition has pressed down on the resources of our medical centers to support clinical research, and the system of clinical research has atrophied. It is critical to translating to basic research into pharmaceuticals and other things that will improve the quality of our health.

Also, for NIH research, please, we have to have some money for contraceptive research.

NIH has to be reminded that that is one of the legitimate areas of research. Because they have dedicated so little attention to it, the private sector dollars have atrophied and, to this day, sterilization is the most common form of contraceptive, 42 percent. It is really an outrage.

Lastly, education; I would urge you to focus on special ed. Increase the money for special ed. Then towns can hire more teachers and fix their buildings and do what they need to do. But if we could somehow find the money to get special ed up to 40 percent, then communities like mine, a small city of 70,000, could have a lot of choices, including private property tax cuts.

Very briefly, the President cut the Services Block Grant money, critical as we try to get people off welfare, cut 20 percent. I know how hard it is to add it back, but if you could that and pay attention to the need for better day-care funding. Those two things, the child care and development block grant money, those two things are critical to the success of welfare reform. If we don't have funding for the vouchers for low-income working people, then we can't support people in getting off welfare. No one can pay day-care for three kids on a

minimum wage job or starting job.

I know how hard it is to get the social service dollars back; and I suppose, in some ways, the day-care dollars are more important, then voucher dollars, but that group of people is really terribly important if independence is going to succeed. Thank you very much for your attention.

Mr. Porter. Thank you, Congresswoman Johnson.

We will stand in recess for these votes.

[The prepared statement of Congresswoman Nancy L. Johnson follows:]

[Pages 2196 - 2199--The official Committee record contains additional material here.]

Thursday, April 30, 1998.

WITNESS

HON. CHARLIE RANGEL, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

Mr. Porter. The subcommittee will come to order.

We continue our hearings of Members of Congress, with the Congressional Black Caucus; and Congressman Rangel, for the moment, you are able to----

Well, Congresswoman Millender-McDonald has already testified. She can testify again if she would like.

Ms. Millender-McDonald. With reference to HIV and AIDS.

Mr. Porter. No, this is the Black Caucus. Then we are going to have the Women's Caucus after that.

Ms. Millender-McDonald. However, I am a member of the Congressional Black Caucus.

Mr. Porter. Well, you can talk on either one. Why don't you testify now on whatever you would like to add to what you testified to before?

Mr. Porter. Representative Rangel.

Mr. Rangel. Mr. Chairman, thank you so much for having these hearings and allowing the Congressional Black Caucus to be here and also to, once again, publicly thank Mr. Stokes. In my opinion, Mr. Stokes will always be with us. Mr. Chairman, I would like to thank him for his sensitive leadership and inspiration he has given to our Nation over the years he has served and, most importantly, on this committee.

It is always a problem when someone is testifying and wondering how far they have to go in the facts because they don't know whether the person listening understands how serious the problem is. But when you see that Lou Stokes is around and the life that he has given to these problems in trying to find some solution, it makes our political lives and legislative lives a lot easier.

I am here to advocate that, wherever you can, try to find adequate appropriations for education and drug rehabilitation. I cannot think of a more serious problem that our Nation is facing as we move into the next century than the moral indictment that we have in jail of a million and a half young people.

I remember when I was briefed before I went to Cuba with the Pope, and I was asked, if you see Mr. Castro, make certain you bring up the question of political prisoners. I said I don't mind bringing up that question, but what happens if they ask us about our one and a half million political prisoners?

Because the truth of the matter is that we are talking about hopelessly unemployed young people that really have given up on their lives, and we find our country moving more to give priorities on the local, State and Federal level to jails than they are to education. It seems to me that we cannot sit down at the table of international competition with this heavy burden on us, losing out on productivity, losing out on revenue and that, at our present costs, just talking about the jail maintenance, of \$350 billion a year.

In New York City, we pay \$84,000 a year to keep a bum kid in detention, and it is hard for us to get more than \$7,000 a year to keep a kid in school. If we can get these youngsters in school to even dream and to believe that they can become part of the general society--these are the kids that are not making the babies, doing the drugs and doing the abuse. They are dreaming, they are moving and they are providing an exciting contribution to America.

But if we give up on these kids in school, and the school budgets are a total disaster, then they find themselves in the street, without role models, without jobs; and, quite frankly, drugs and violence is not a serious problem for them to deal with as many, many kids are going to more funerals than they are to graduations.

I don't know what it is going to take to jolt this country into believing that this is not just a racial community problem, it is a national problem. It has economic impact.

This committee has the ability to establish priorities through appropriations. We can go to the floor and talk about what is not happening in the District of Columbia, but I had hoped that maybe if they made the District of Columbia a model city, with model public schools, with model job training and model opportunities, as we have the greatest minds in the world here in the Nation's Capital, that maybe the other cities could see the potential that we have.

But if we are going to fight as to who is getting the next prison and ignore the needs of our kids, you can be assured that the prison population will increase and that our competitive edge will decrease, and the differences between those that have and those that don't have is going to widen, and when the kid doesn't give a darn about living, then the rest of us got a heck of a problem to live with.

So, Mr. Chairman, you have proven your sensitivity on these issues. I guess the real question is, what can we do to get the message out there that this is not a parochial interest; indeed, it is a national security interest.

Once again, Mr. Stokes, you have done far more in the time you have been here than I could ever dream about doing; and I guess all of us will have to try to get together and fill the big shoes that you leave here.

Thank you, Mr. Chairman.

Mr. Porter. Thank you, Congressman Rangel.

[The prepared statement of Congressman Charles B. Rangel

follows:]

[Pages 2202 - 2204--The official Committee record contains additional material here.]

Thursday, April 30, 1998.

WITNESS

HON. MAXINE WATERS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mr. Porter. Congressman, Millender-McDonald.

Ms. Millender-McDonald. I would like to refer to our chairwoman for her remarks.

Mr. Porter. Congresswoman Maxine Waters of California.

Ms. Waters. Thank you very much. I appreciate that.

Chairman Porter, I appreciate the opportunity to be before you this afternoon. But, I certainly do appreciate Congressman Stokes, who organizes this panel of the Congressional Black Caucus every year. Not only does he provide leadership as we address our needs here in appropriations, but he provides leadership for all of us in our caucus and, of course, in the Congressional Black Caucus as well as the Democratic Caucus and this entire House. As a matter of fact, each time I have to admit that he is retiring, it makes me sad, because his leadership is going to be sorely missed.

Let me just say, having the opportunity to come before you today, I would like to follow up on the testimony that you just heard. Each time you have seen me come, I have made a case for funding our efforts to get rid of drugs in our community.

It is no secret to anybody that the Congressional Black Caucus, in the development of its agenda for the 105th Congress, made the eradication of drugs our number one priority; and we have been saying it over and over again, not only in all of the relevant appropriations subcommittees and committees but in all of our public speeches and everything that we do. We have tried to sound the alarm that America must be about the business of dealing with the eradication of drugs.

So with that being our number one priority, with 27.8 million Americans needing treatment, the untreated substance abuse costs America more than \$167 billion annually in lost productivity, law enforcement, criminal case processing and health care.

We are here in support of SAMHSA. The President's request is \$40.5 million, but particularly important is the request to increase the substance abuse block grant by \$200 million. We think this is very critical to meet the current treatment gap.

Federal block grants provide about 44 percent of all national funds for substance abuse and supports treatment for some 3.8 million persons, and it is vital for local and State organizations and agencies trying to help people take back their lives from the ravages of drug addiction and prevent our youth from turning to drugs.

Let me just move on. We have had a debate on the floor of Congress, I guess it was just a day or so ago, about needle

exchange. Well, whether we approach the problems of HIV and AIDS from one direction or the other, there are people who believe that needle exchange will make a difference. There are people who take the opposite point of view. The fact of the matter is, we have got to be serious about this issue. We have got to take our heads out of the sand. There are dramatic increases in HIV/AIDS infection and really is devastating the African American and minority communities.

AIDS is now the number one killer of African Americans between the ages of 25 and 44, and we believe that the Federal funds must go where the problem is.

What we are finding, in addition to all the work we do here to try to get those funds into our communities, something is wrong in the system that is not allowing our local groups to access the dollars in the way that they should.

I called together all of the AIDS groups in my community over a year ago to find out why I was constantly getting calls about the inability to get dollars to deal with the problem. Well, what I discovered was this:

When the money goes down from the Federal Government to the State, each of the States have different systems by which to get the money into the community, and you have got to now be sophisticated and learn how these systems work, and the people who manage the systems have got to be open to allowing new people to come in and not just those who started early in this funding game.

So the commissions and the task forces that design the RFPs and change the direction, sometimes from treatment, from outreach to treatment, they do this oftentimes without some of the very local groups knowing what direction the funding is going in, and they miss the ability to respond to a request for a proposal, and they are left out there trying to serve populations.

I think, as we look at this funding, we are going to have to be advocates for several things, technical assistance and the kind of outreach and education that will help to teach communities about the systems that impact their districts.

In addition to that, let me make a case for the trauma that we are experiencing in the African American community as it relates to almost every disease that you can mention.

The papers are constantly reminding us or alerting us to the fact that African Americans are dying at high rates for cardiovascular diseases, HIV and AIDS. We are high on the list for diabetics, even though I don't think we are number one. But we are right up there with a lot of amputations taking place, you name it.

In almost every category of disease, African Americans are number one, and we get less treatment. We can't get the transplants, many of the life-saving therapies and new technologies that can save lives. We are the last to get it.

I was reminded of this attending the Health Brain Trust that has been led by Mr. Stokes for so many years, and I sat there, and I became overwhelmed with hearing the information one more time. So the President, as part of his race initiative, has included a proposal for \$80 million to set up some demonstration projects, to foster more outreach and access to health care in minority communities. This is desperately

needed.

African Americans are dying from preventible diseases, and the money that the President is requesting would be a portion between the Centers for Disease Control and the National Institutes of Health and other agencies within Health and Human Services.

I wish that I could come before this committee this year or in the next few years and say, Mr. Chairman, it has been done, we are making headway, but today I can't say that. Today I am overwhelmed, somewhat frightened, but determined that we direct the resources toward these problems, that we get on top of the problems; and, of course, your decisions are crucial and critical to our ability to do that.

I appreciate your listening one more time, but I would appreciate even more your support for these and other initiatives that will help with the problem.

Mr. Porter. Congresswoman Waters, thank you for your statement.

[The prepared statement of Congresswoman Maxine Waters follows:]

[Pages 2208 - 2209--The official Committee record contains additional material here.]

Thursday, April 30, 1998.

WITNESS

HON. JUANITA MILLENDER-McDONALD, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mr. Porter. You are the chair of this panel. I would plan to call on people in the order of their arrival, but you might want to vary that. I will follow your lead on that.

Ms. Waters. Oh, please, in the order of arrival would be fair.

Mr. Porter. That would be Congresswoman Millender-McDonald.

Ms. Millender-McDonald. Thank you so much, Mr. Chairman; and let me please associate myself with the testimony that has taken place here already.

We do know that education is the liberating tool that would bring people out of welfare to work. We recognize that under the rubric of education comes job training, comes counseling, comes after school programs; and we are really encouraging you to encourage all those on this panel, on this committee, to be sensitive to the needs.

We come here every year asking for the same thing, so, obviously, that money is not coming down to where it is really needed. It is needed solely in our communities. We are trying to fight the drugs, HIV and other serious diseases; and we cannot do that without help, without resources, financial and other resources. So I just ask you, you have been very sensitive to the requests that I have made before your committee since I have been here, and I ask that you continue to do that.

We are losing a giant among us. Mr. Stokes has been a

national leader. I knew him before I got here, and I tell you, I look up to him all the time, not because he is six whatever but because he has made giant steps in this House, and he has certainly served us well. We want to continue to make sure that his presence is here on this committee when we come before you touting the critical concerns that we have about the ills of our community.

I did not come with a prepared speech, but when you call the Congressional Black Caucus, of course I am a member of that, and I do thank you very much for this opportunity.

Mr. Porter. Thank you, Congresswoman Millender-McDonald.

Thursday, April 30, 1998.

WITNESS

HON. JOHN CONYERS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MICHIGAN

Mr. Porter. Next would be Congressman John Conyers.

Mr. Conyers. Thank you, Mr. Chairman.

Say it isn't so, Lou. We may have to use extraordinary means to get you to reconsider. This is one of the few times I have disagreed with your judgment in these 20-something years.

But I come here on a local note, just to tout where some of these Health and Human Services appropriations go in the Departments of Labor and Health and Human Services. In Detroit, there are three areas that I just want to mention; and my remarks will be in the record.

The Focus: HOPE job training center, that serves as an international model, Mr. Chairman. They started off with the late father, Bill Cunningham, started off feeding, and then he went into pharmaceuticals, and then he started doing some kind of job--he was getting a few labor grants for jobs, and then he started pulling in the retiring vice presidents and sometimes CEOs of the auto corporations, and then the training program grew from just apprenticeship to an engineering-certified, degree-granting institution. We have had everybody in there from the President and Colin Powell; many of our colleagues have come in. The late Secretary Brown took this plan over to South Africa to present to President Mandela's government. When the students finished this really grueling program, they walked across the stage into the arms of an employer.

If you have an engineering degree from Focus: HOPE, you have a degree that is more welcome in the ranks of the auto industry than the degree-granting institutions of Wayne University, U of M, and MSU. Because this has been developed by auto management executives, so it is tailored exactly for what they need this kind of skill for.

The other success story in metro Detroit is the Job Corps Center. It has really done great work with kids through 16 to 24. They receive a basic education plus vocational education, plus counseling, plus placement. So it is a really gratifying institution.

The other is the medical grants that have come our way. Henry Ford Hospital has research grants for vision research, so it was no accident that the senior senator of Michigan brought

the Chinese dissident, Wang Dan, who was flown straight into Detroit to the Henry Ford Hospital, for the very necessary treatment that he needed.

On the policy front, we are asking the committee to look into the inability of HHS to allow its community development corporation grantees to retain their assets, which of course allows them to grow. Example, if a development corporation happens to make a profit off of their enterprise, it shouldn't be required to return the money to HHS. I mean, it seems to me that this undercuts the entrepreneurial spirit that we spend a lot of time around here promoting. Development corporations ought to be permitted to retain and reuse the money.

So I am happy to join and affiliate myself with the remarks of our chairperson, of the gentlelady, Ms. Millender-McDonald, from Los Angeles, and all of us who have really, under Mr. Stokes' guidance, have provided some of the fundamental basic policy directions in the delivery of all of these very important services in health and in labor as well.

Thank you for allowing this intervention.

Mr. Porter. John, thank you very much.

[The prepared statement of Congressman John Conyers, Jr., follows:]

[Pages 2212 - 2213--The official Committee record contains additional material here.]

Thursday, April 30, 1998.

WITNESS

HON. EDDIE BERNICE JOHNSON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS

Mr. Porter. Next, Congresswoman Eddie Bernice Johnson of Texas.

Ms. Johnson. Thank you very much, Mr. Chairman.

I serve as an officer in the Caucus and the vice chair of the Health Brain Trust of the Caucus; and I want to just say, very quickly, the uniqueness of program needs for the minority community is that the population that is becoming infected by HIV/AIDS now is a population that many of us don't come in direct contact with. It is not like addiction to smoking where professionals will see other professionals and they can talk about it or even the addict that is a professional.

This is a unique population because you have to go into very difficult areas, into specific communities and neighborhoods and areas to attempt to find the people.

Many of the addicts, and this is what is causing most of the infection now with women and children, don't have that information. That was the value of having the needles. Because just as you can't stop smoking without help and you can't stop prescription drug addiction without help, you really cannot stop other drug addiction without help. It becomes an illness. It becomes a way of life. So that is one of the uniquenesses, that any poor population, especially a minority population, has to be individually targeted in order to touch that particular

population.

What we are dealing with now is block granting going to the States. We don't have as much expertise in the black community in grant writing. We have not had the experience. We have not been doing it as long. And, as a consequence, our population that is infected is growing very, very rapidly.

It is being transmitted through sexual contact and needle infection of men to wives and children. We have the largest number of children being born infected with that virus. The incidence among black women now is higher than their population percentage in the population. It is serious.

Somehow we have got to educate our colleagues well enough to understand that some specific areas must be considered when you are attempting to get to a population that cannot be accessed in any other way except one on one, people actually going to the street and finding these people and going into particular isolated neighborhoods, where they tend to be, and without the knowledge of how they can help themselves and often without the knowledge that they even carry the virus.

I thank you so much for your past consideration. I thank you for the time.

Mr. Porter. Thank you, Congresswoman Johnson, for your good statement.

[The prepared statement of Congresswoman Eddie Bernice Johnson follows:]

[Pages 2215 - 2226--The official Committee record contains additional material here.]

Thursday, April 30, 1998.

WITNESS

HON. DONALD PAYNE, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY

Mr. Porter. Congressman Don Payne.

Mr. Payne. Thank you, Mr. Chairman.

Let me say, first of all, that we really appreciate the support that we have gotten from this subcommittee through the years and appreciate your interest in our issues, and we are simply Stokes soldiers out here trying to carry this on to victory. I don't know what we are going to do without our esteemed leader, but we will have to come up with--maybe it will take 10 of us to step in his shoes, he is such a great man.

Let me also commend the Chairperson of the Congressional Black Caucus for her fine leadership.

Let me just move quickly into a statement that we all know that we are privileged to be living in a time of great prosperity in this country, experiencing unprecedented economic growth and the lowest unemployment rate in decades. Unfortunately, this prosperity has not spread to our inner cities. In fact, the overall unemployment rate for African American teenagers continues to hover around 30 percent. In urban and rural areas of concentrated poverty, joblessness is

even more pervasive.

Surveys conducted by the Department of Labor and selected inner city neighborhoods in Chicago, Houston, Los Angeles, found unemployment rates for out-of-school youth of only 39 percent, with only 29 percent employed full time. Now is the time the economy is strong to begin addressing the issues of joblessness and poverty in our Nation's most impoverished areas. If we can't do it now, we will never be able to do it.

The effects of joblessness and poverty on our society are staggering. I believe that education and employment are the keys to fighting poverty in racial and ethnic inequities in our country.

Therefore, I come before the subcommittee today to support the Department of Labor's \$250 million appropriation for the President's Youth Opportunity Areas initiative. This initiative specifically addresses the issues of poverty and joblessness. It targets funds directly to high-poverty urban and rural areas, and its goals are to increase the employment rate of out-of-school youth ages 16 to 24 in high-poverty neighborhoods from the current levels of less than 50 percent to a level of 80 percent--that is in the goals of this bill--equal to what we would find among youth with at least a high school diploma in nonpoverty areas. The Department of Labor estimates that 50,000 youth could be served at this funding level of \$250 million.

The Youth Opportunity Areas initiative should have strong appeal to both Democrats and Republicans, because its main emphasis is work, and I think all of us believe fundamentally in the importance of work and work effort. It also has a strong emphasis on the private sector for employment, so, therefore, the core of this initiative is working to place and keep out-of-school youth in private sector jobs.

The Department of Labor has made three initial pilot programs. One is in Boston, one is in New York City, and one is in rural Kentucky.

The Houston site, in particular, is very promising because the program has 14 case managers. Job developers are working with youth. They have placed 220 persons in jobs, 150 other youngsters are working in other areas, 78 are enrolled in job training, and 60 have GED classes, and another 60 are at the point of getting work. This is a specific pilot that we could look at. It is quantitative. We can see that it works.

So, once again, I just appeal to you that the Youth Opportunity Areas pilot sites could be duplicated and replicated if we can get the \$250 million that the President is asking for.

I have some other material, but since there are other members of our committee I would simply, once again, thank the committee for allowing us this opportunity, once again, we appreciate your previous support; and we hope it continues in the future. Thank you very much.

Mr. Porter. Thank you, Don.

[The prepared statement of Congressman Donald M. Payne follows:]

Thursday, April 30, 1998.

WITNESS

HON. MAJOR OWENS, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

Mr. Porter. Next, our colleague from New York, Representative Major Owens.

Mr. Owens. Mr. Chairman, members of the committee, I want to thank you for this opportunity; and I am going to be brief and not repeat things you know very well.

I want to talk about the TRIO programs, and you are quite familiar with that. You have been a guardian of this program and nurtured it along through some very difficult periods while other programs were being cut. I am here to talk about the fact that everybody agrees on the Education and the Workforce Committee that this is an exemplary program that works. The Higher Education System Act is now being considered on the floor. We were there until midnight last night, I understand, and will be back next week.

It is important to note that H.R. 60 is basically a good bill. My problem is, I think we missed some golden opportunities to move forward; and, most of all, we should have provided more opportunities for more people to go to college.

When you consider how complicated the world is becoming and the fact that we can point to specific areas where there are large shortages now of trained personnel, especially in the information technology industry where there are now about 300,000 vacancies right now and they expect, in the next 3 or 4 years, you will have as many as a million vacancies--these are unfilled positions. They project there won't be people coming out of college who will fill them if you keep the present number of people in college at the same level.

We need more people going to college. It is true we have a lot going in this country, more than most industrialized nations, but still less than 10 percent of the population goes to college. Certainly we want the segment of the population that has been locked out before, those people whose parents didn't go to college are the ones that TRIO focuses on. TRIO, which now, as you know, is no longer TRIO, it is about six different programs, but the heart of TRIO is still Talent Search and Upward Bound, and it works.

The authorizing committee did a very unusual thing when we had it before us. We voted unanimously, both parties, to increase the TRIO program from the level of \$560 million down to \$800 million. The authorization has been raised to \$800 million by unanimous consent on the authorizing committee, which held fast and didn't increase anything else, by the way. But it recognized it works.

There was a discussion, some people felt the TRIO programs have proceeded very well, and they wanted to disqualify and defund some of the existing programs so that new areas where people had been disadvantaged and are not as sophisticated and didn't get in on the proposal writing and qualify first, they should be given preferential treatment and funded instead of

the old areas.

We are not in favor of that, and that was rejected by the committee. Instead, we unanimously authorized an increased amount of money. And although we didn't have a vote on it, there was a general sentiment that the increased money, the new money, should go to areas, and they should be picked on the basis of the most disadvantaged areas that had been left out before, who had not been funded before, and some kind of system should be developed to guarantee those people get a fair share.

So we would like to see the Appropriations Committee, which has always been very supportive of TRIO, follow through on the unprecedented, bipartisan cooperation of the authorizing committee and sustain the \$800 million funding we have asked for.

I would appreciate your efforts in direction.

Mr. Porter. Thank you, Major.

[The prepared statement of Congressman Major Owens follows:]

[Pages 2236 - 2241--The official Committee record contains additional material here.]

Thursday, April 30, 1998.

WITNESS

HON. ROBERT SCOTT, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF VIRGINIA

Mr. Porter. Congressman Robert Scott of Virginia.

Mr. Scott. Thank you, Mr. Chairman.

I am pleased to join my good friend, Louis Stokes, in his tireless effort to improve the health of disadvantaged individuals and groups. I am sure you will agree with me when I say that, as a result of his efforts and leadership, there is a much greater awareness in Congress and in the Nation of the health needs of disadvantaged children and adults.

We held a Congressional Black Caucus Brain Trust on Health last Friday; and, unfortunately, it went much longer than we had anticipated because all of the 200 participants there felt individually compelled to go on and on about the accolades for the leadership and hard work of the chairman of that Brain Trust, Congressman Stokes, and how disappointed they were at the news he is not seeking reelection. And because of those accolades--I mean, you tried to stop it, and somebody else would jump up and go on and on about the hard work. So we have a lot of work to do in joining the others in expressing their dismay that Congressman Stokes is not running for reelection.

Mr. Chairman, while the health status in the general population of the United States has improved, the health indicators for minorities overall and African Americans in particular have not kept pace. We heard at that Congressional Black Caucus health forum a long list of disparities in health status indicators between disadvantaged minority populations and the general population.

There are three specific initiatives before the

subcommittee that will help close those gaps: the Healthy Start program, Minority Health Professions Training Initiative, and the Youth Violence Prevention.

The Healthy Start program has been recognized and funded by this subcommittee, started as a program to improve infant mortality rate in high infant mortality communities. It has brought a significant drop in infant mortality and low birth weights.

The second initiative, research has shown that most health care to minorities is provided by minority health professionals. So another way to effectively address the disparities in health status is to increase the number of minority health professionals. The program, under the Disadvantaged Minorities Health Improvement Act of 1997, designed to increase the number of minority health professionals, is an important initiative to achieving that goal.

I would also ask that the subcommittee support funding of the Youth Violence Prevention Initiative, developed by the gentleman from Ohio. Violence has reached almost an epidemic proportion in some of our communities, and far too much of it involves young people on both sides of it. Research has shown that early, comprehensive, family-based interventions for at-risk youth will have a significant impact in reducing violence and other crimes and at a much lower cost than the ineffective, after-the-fact approaches on which we are now spending billions of dollars.

Mr. Chairman and Mr. Stokes and Ms. DeLauro, I appreciate the opportunity to provide this testimony and hope you see fit to fund the Healthy Start program, the Minority Health Professionals Training and Youth Violence Prevention Initiatives.

Thank you, Mr. Chairman.

Mr. Porter. Thank you, Bobby.

[The prepared statement of Congressman Robert C. Scott follows:]

[Pages 2244 - 2247--The official Committee record contains additional material here.]

Mr. Porter. Lou might be reconsidering his decision here. I don't know. Lou, would you like to respond?

Mr. Stokes. Thank you, Mr. Chairman.

Mr. Chairman, let me take just a moment. You have been very gracious with your time that you have extended to each of my colleagues; and I don't want to take up too much time, particularly knowing you have got to make a very important call.

But, I do want to take just a moment to say to my colleagues in the Congressional Black Caucus how much it has meant to me that, each year when I have requested you to appear here as a panel, that you have been responsive in coming here and testifying on the programs that you have addressed here this afternoon.

It has been difficult over the last 20 years to sit here

each year, day after day, year after year, listening to the testimony of the secretaries of the various departments, the heads of all the NIH departments, as they, in response to questions posed by me, reiterate the devastating condition of minorities in this country. Whether it be in the area of labor, health, human services or education, we are the bottom rung of the ladder.

I need not say that to you because I know, on the committees where you work, you are carrying out the same type of work that I carry out here, pointing out the disparities in life in America for minorities. So your presence here today is very, very important to me.

Many of the programs you have responded to, I have to give credit to this subcommittee. I don't know of any subcommittee or committee in the Congress that has been more responsive than this committee has been to the kind of concerns that I have expressed and you have expressed here today.

In particular, I want to commend Chairman Porter. He and I have sat on this committee together many, many years, even before he became chairman of this committee, but he has always been responsive and sensitive to these areas of concern which you have addressed here today, and I want the record to show my appreciation for his response to these areas.

While I will not be here to carry on this fight, as I have in the past, it will be extremely important in my absence that you continue to be as vocal and as articulate and as vigilant as you have been in the past to see that this type of concern and sensitivity is brought before this subcommittee.

I thank you for your appearance.

Mr. Porter. Lou, it hasn't been the subcommittee or the chairman, it has Lou Stokes and his advocacy, believe me; and you know we are going to miss you and the leadership that you have provided.

Mr. Stokes. Thank you, Mr. Chairman. Thank you.

Mr. Porter. We will have a chance to dwell on that a little bit more.

Ms. DeLauro.

Ms. DeLauro. Very, very briefly, I would like to say to the Black Caucus what an honor it has been for me to serve on this committee with Lou Stokes. I sit at this end, and he is there, but he is always a mentor.

I listen carefully when he speaks, and don't let anyone be misled, he knows the absolute big picture. He focuses in on the questions about what is going on in the lives of minorities, men, women and children, in this country. Those issues have always been at the forefront of his agenda. He has taught me a lot, and I will deeply miss him. He has been a mentor to me.

And I say to the Black Caucus, whether it is education or the TRIO or the drug issue and so forth, whatever happens in this committee, everything affects everyone's lives personally when it comes before us. You have focused foursquare on making sure that those are the issues that you spend your time and your emphasis on. Thank you for being here, and we will do the very, very best we can for you on this committee.

Mr. Stokes. Thank you.

Mr. Porter. Ms. Lowey, do you want to add anything at this point? You certainly may.

Mrs. Lowey. First of all, I want to apologize for not being here for my good friends' testimony; but I have worked with these outstanding Members of Congress; and I can almost write the testimony, knowing that they care passionately, and I mean passionately, about the issues we are dealing with.

The only problem with this committee is there is a constant trade-off between the great issues we all care about. We care about schools, we care about education, and we care about child care. We would like to make sure that our schools are open until 7:00, all of them, so we can have real, constructive after-school programs and child care within the schools.

So I just want to thank you for your advocacy, thank you for your agenda, thank you for your heart, thank you for your commitment, and I just want to assure you that there are many of us on this committee that are going to continue to advocate for your agenda because we care as well.

We are all so sad that our star is going to be retiring. Lou Stokes has not only been a star in the entire Caucus but he is such an eloquent advocate on this committee, a good friend of ours, and we are going to miss him. We will work very hard to try to achieve just a fraction of what Lou Stokes has achieved in the service to this committee.

So I want to thank you for appearing before us; and we thank you, Lou Stokes, for being on our committee; and we will try and work hard to carry on your good name. Thank you.

Thank you, Mr. Chairman.

Mr. Porter. Thank you, Ms. Lowey.

Thank you everybody who has testified.

Mr. Scott.

Mr. Scott. I have testimony I would like to have as part of the record that goes in a little more depth than my statement.

Mr. Porter. Without objection, it will be received.

Mr. Payne. Mine also, Mr. Chairman.

Ms. Waters. Thank you very much.

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Thursday, April 30, 1998.

WITNESS

HON. ELEANOR HOLMES NORTON, A DELEGATE IN CONGRESS FROM THE DISTRICT OF COLUMBIA

Mr. Porter. Some of you are also staying for the next panel, the Congressional Caucus for Women; and whomever is here, we will next hear from.

Ms. Norton, you are the chair, are you not?

Ms. Norton. Yes.

Mr. Porter. Well, we will next hear from the Congressional Caucus for Women; and we are pleased to welcome the Chair, Congresswoman Eleanor Holmes Norton of the District of Columbia.

Ms. Norton. Thank you very much, Mr. Chairman. I hope you will indulge me so that I can say at least a half a minute about Mr. Stokes. Because of a dinner in my district, I may have to leave before all of my colleagues in the Caucus testify.

That special word, Lou, is simply that if there was a tradition in the House of hanging up and retiring the shirt, yours would have to be gone. We are going to leave your chair there, but, for some of us, it is going to be a chair that will never be filled. The esteem in which you are universally held does not come simply because of your remarkable personality. It comes because of your work and your brain and what you have earned in that esteem. You will be missed across this body.

Mr. Chairman, the Congressional Caucus for Women's Issues very much appreciates the opportunity once again to testify before you. Today, we carry on a great tradition in the Women's Caucus in which your subcommittee has kindly indulged us. As we come before you once again to continue the fight for important initiatives which are vital to meeting the needs of women, children and families, we stress the unique bipartisan nature of our Women's Caucus and its strength and solidarity and growing numbers that has helped bring about many changes for women, many of them with the help of this very subcommittee.

This necessarily means, of course, that not all issues are Women's Caucus issues. The issues of this subcommittee, however, are quintessentially Women's Caucus issues.

This year, we celebrate a record number of women in the House. We are 55 strong and growing. All three special elections this year were won by women. Our growing numbers have strengthened our issues and strengthened our resolve.

For the first time in 20 years, the Women's Caucus initiated informational hearings of its own in the 105th Congress to put us on the cutting edge of issues for women, children and families. All of our hearings share individual subject matter under your purview. We have had hearings on child care for 0 to 3-year-olds, contraceptive research, coverage and technology, Title IX, Federal procurement for women-owned businesses in a town meeting on economic equity.

Earlier today, we had our latest informational hearing on exciting new developments in drug technology for the prevention of breast cancer. The Tamoxifin breakthrough on breast cancer is the kind of issue we particularly seek for our own informational hearings.

No subcommittee has proved more critical to our work than this subcommittee. We want to offer our very special appreciation for the way in which you, Mr. Chairman, and this subcommittee have been responsive to the concerns of women and families.

Members will be testifying today about issues of special concern to them personally. Our co-chair, Nancy Johnson, will be testifying about Title X, an issue of great importance to our Caucus.

Through our hearings on contraceptive research, we learned publicly funded family planning prevents 1.2 million unintended pregnancies a year.

There are a few members who have had to leave, and I won't call their names because they will be submitting testimony directly to you, Mr. Chairman.

The former co-chair of the Caucus, Representative Connie Morella of Maryland, will testify about osteoporosis, AIDS and domestic violence. Representative Eddie Bernice Johnson of Texas will testify about HIV and AIDS. Representative Juanita

Millender-McDonald of California will testify about telemedicine. Representative Carolyn McCarthy will testify about breast cancer. Representative Sheila Jackson Lee of Texas will cover domestic violence. Representative Lucille Roybal-Allard of California will identify her concerns in her testimony.

Mr. Chairman, I would like to conclude by thanking you and the ranking member for the extensive work you have done through these tough budget years to salvage the priorities of women and families. We appreciate just how difficult this task has been. We urge you to focus on and to emphasize the important priorities we bring to you today and that we think fairly represent the priorities of women in the country.

Thank you very much, Mr. Chairman.

[The prepared statement of Delegate Eleanor Holmes Norton follows:]

[Pages 2252 - 2262--The official Committee record contains additional material here.]

Mr. Porter. Congresswoman Norton, you are the chair and if you wish, you can call on members in the order you wish to present them or I will call them in the order in which they arrived.

Ms. Norton. You may do that, Mr. Chairman. I prefer you do that, except Ms. McCarthy apparently has to get a plane.

Ms. McCarthy. I have to get a vote first.

Ms. Norton. Well, then I think they shouldn't be called out of order.

Mr. Porter. Congresswoman Millender-McDonald has been with us all afternoon, and this is her third appearance, so she is next.

Ms. Millender-McDonald. Does that mean I get a seat up here perhaps?

Mr. Porter. Pretty soon, right.

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WITNESS

HON. JUANITA MILLENDER-McDONALD, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Ms. Millender-McDonald. I thank you so much, Mr. Chairman and members and all of the women on this great committee, for the opportunity to bring together the women of the House, who I am proud to say are now 55 members strong.

Although I would like to discuss the dire need of school construction, the climbing rate of teen pregnancy, the serious health disparities that exist for minorities and women and numerous other important health and education issues, I will limit my comments to the problem of AIDS.

Just this past weekend, I led the Second Annual AIDS Walk for Minority Women and Children in Los Angeles to address this

issue in my community and the State of California. While the number of national AIDS cases declined among most populations in the past couple of years, the number of cases actually increased among women by 2 percent.

African American women are nearly 15 times more likely to have AIDS than that of white women. Women die 33 percent faster than men from AIDS. This is a dangerous national trend that is hitting the 37th district of California particularly hard. In Los Angeles alone, there are an estimated 25,000 AIDS cases.

Earlier today, I shared with you a remarkable resource for inner cities that is run by Drew University in my district, the first-ever urban telemedicine project in the country. In treating and preventing severe loss of vision and blindness resulting from AIDS, telemedicine is just one of the many ways underserved communities can obtain the medical care they need.

The other resources that are critical in lowering not just the death rate but also the transmission rate among women and children include allowing States to fund needle exchange programs and providing the necessary funds for the Ryan White CARE Act.

Particularly, I am requesting a \$105.2 million increase from last year's appropriation for Title I and a \$36.7 million increase for last year's appropriation for Title III.

There are 51 metropolitan areas eligible to receive Title I funds that provide emergency assistance care to 74 percent of all reported AIDS cases in the United States. Each year, HRSA estimates 20 percent of Title I clients are new cases.

Title III of the CARE Act serves the hardest to reach communities. Approximately 80 percent of Title III clients have incomes below 300 percent of the poverty level, and 25 percent of Title III HIV patients are women of child-bearing age.

These Title III primary care programs in 43 States provide early diagnosis, treatment and ongoing care for people with AIDS, which extends lives and saves money. Early diagnosis and treatment for almost 100,000 people reduce hospitalization by up to 75 percent.

I need not go on and on. It is also important that you know of the funding that is critically needed for AIDS and the drug assistance program under Title II; and I thank you, Mr. Chairman, for your sensitivity to this issue.

Mr. Porter. Thank you again, Congresswoman Millender-McDonald, for your good testimony.

[The prepared statement of Congresswoman Juanita Millender-McDonald follows:]

[Pages 2265 - 2266--The official Committee record contains additional material here.]

Thursday, April 30, 1998.

WITNESS

HON. EDDIE BERNICE JOHNSON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS

Mr. Porter. Congresswoman Eddie Bernice Johnson of Texas.

Ms. Johnson. Thank you very much, Mr. Chairman, for allowing me an opportunity to speak on behalf of the Women's Caucus on the critically important issue of HIV/AIDS and its devastating effects upon American women.

The number of AIDS cases among women is swiftly increasing and growing more rapidly than in men. Women are the fastest-growing population of HIV-infected persons, and the number of AIDS cases among women is doubling every 1 to 2 years.

The Centers for Disease Control preliminary data indicates HIV/AIDS continues to be the fourth leading cause of death among women 25 to 44 years old. In 1995, African American and Latino women represented 78 percent of all U.S. women diagnosed with AIDS. A recent report on the AIDS epidemic in Dallas County, where I reside, revealed the proportion of African American women living with AIDS is greater than the proportion of African Americans in the general population.

Federal funding for biomedical and behavioral research is crucial in order to combat this disease. Research priorities for HIV/AIDS must include studies that identify patterns of behavior and social conditions among cultural and age-based groups of women that determine their risk of infection. Serious focus must be placed on issues such as power in various relationships, physical and sexual abuse, substance abuse and economic inequities between men and women.

In fiscal year 1998, Congress provided welcomed increases in HIV/AIDS research prevention and care. However, more is needed if we are to combat this ever-evolving epidemic and take full advantage of the medical advances that are beginning to emerge; and I would certainly urge this committee to support funding for the Centers for Disease Control and the National Institutes of Health. The agencies must receive the highest priority in order to address this number.

I am close to this issue because of my profession. I understand the devastating effect it has on the entire population and certainly these people and their families.

Through the increased funding of the Ryan White Program and prevention activities initiated by NIH and the Centers for Disease Control, I believe it will be accomplished and that we can find a vaccine and that, eventually, we will find a cure.

So, again, I thank you very much for your sensitivity and interest in this.

Mr. Porter. Thank you, Congresswoman Johnson.

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WITNESS

HON. CAROLYN MCCARTHY, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

Mr. Porter. We have a vote on, and we have probably 6 or 7 or 8 minutes.

The order that I have is Carolyn McCarthy, then Sheila Jackson Lee and then Connie Morella.

Congresswoman McCarthy.

Mrs. McCarthy. I am known to be extremely fast.

Mr. Porter. You have been very patient. You have been here a long time.

Mrs. McCarthy. I will submit my full testimony.

I am here to represent the women certainly of this country but also the women of Long Island and New York State on breast cancer. Unfortunately, on Long Island, we have an extremely high rate of breast cancer. Many of us feel it has to do with our environment; and we are looking for, obviously, funding, again, within NIH to look into this.

Not only does breast cancer affect women, it affects all the families. I myself am a nurse, and I know a lot, and I examine a lot. Every year I go for my mammogram, I always wonder, am I going to be next? We have one out of nine women on Long Island that come down with this terrible disease. I happen to believe research can come up with why are we getting it.

Only 10 percent of women actually have breast cancer because of their genetic makeup. There are many other reasons. We have to find this out. The money we spend on research and maybe the connection between environmental causes will save this country billions and billions of dollars through, certainly, our lifetime. I just want to put my strong support onto research.

I don't envy any of you in your jobs. I sit here listening. Every single project that we have is important to the people of this country; and, unfortunately, you have to make those choices. It is tough, and God bless you.

Mr. Porter. Thank you, Congresswoman McCarthy.

[The prepared statement of Congresswoman Carolyn McCarthy follows:]

[Pages 2269 - 2270--The official Committee record contains additional material here.]

Thursday, April 30, 1998

WITNESS

HON. SHEILA JACKSON-LEE, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS

Mr. Porter. Sheila Jackson-Lee of Texas.

Ms. Jackson-Lee. Mr. Chairman, thank you very much; and we should offer our great appreciation for this committee's work. It is the heart and conscience of America, seriously, on the kinds of programs--and let me associate myself with the remarks of the Congressional Black Caucus and the Chairwoman of the Women's Caucus and tribute to Lou Stokes. I would want to stand up and retire shirts and say a whole lot of things, but I hope we will have times to come. And the women on this panel, in particular, I do thank you for your leadership.

I would like to talk in a bionic minute to say the domestic violence programs are enormously important; and I would like to submit into the record, if I could, more information on that.

Ms. Jackson-Lee. Because I have an additional cause I would like to raise to this committee's attention, and it impacts women. It is the Comprehensive Community and Mental Health Services for Children and Their Family's program. This actually deals with mothers and families but children with emotional disorders. Eleven million children who need to be diagnosed in

this country are not. This legislation was authorized in 1992, and it has not gotten its full appropriations.

I want to thank the committee for what it has done, but we are talking about situations where 1 in 20 children will have a severe disorder by the age of 18 and from ages 9 to 17 may have a serious emotional disturbance as well. The children usually wind up in the juvenile justice system. Suicide is the fourth largest cause of death among teenagers.

This program is only in 22 States and helps to go into communities and work with parents and schools and churches to embrace the child who has an emotional disorder.

I encourage your support along with support for the Head Start program and support for funding for NIH in order to have more testing of the cause of the impact of silicon breast implants, and I would greatly appreciate the committee's review of that issue as well.

Mr. Porter. Thank you, Congresswoman Jackson-Lee.

Thursday, April 30, 1998.

WITNESS

HON. CONNIE MORELLA, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MARYLAND

Mr. Porter. Congresswoman Morella.

Mrs. Morella. Thank you, Mr. Chairman.

I echo everything that has been said laudatory about Mr. Stokes. I am going to miss him as a constituent, too. He used to give me an idea of what was happening in the community, but he has been a great statesman and a very good friend.

Mr. Chairman, you are certainly one of the top congressional supporters of the National Institutes of Health; and I appreciate it very much. I commend you for ensuring such a generous increase of NIH funding in fiscal year 1998 and I know you will continue to make biomedical research a priority.

We ask you continue your strong support for the Public Health Service Office on Women's Health, the NIH Office of Research on Women's Health and the other offices of women's health within the Public Health Service agencies.

I will pick up on the concept of AIDS, too. It continues to be the fourth leading cause of death that was mentioned among young women, the fastest growing group of people with HIV and AIDS. It is the leading cause of death in young African American women.

I particularly urge your continued support for the development of microbicide to prevent the transmission of HIV and sexually transmitted diseases at a level of \$50 million.

Secondly, we urge this subcommittee to provide adequate NIH funding for the Women's Interagency HIV Study, the natural history study of HIV in women.

We commend the increases for research, prevention and the CARE Act in fiscal year 1998 and hope that that momentum will continue into fiscal year 1999.

I also want to point out a couple other items briefly.

Sexually transmitted diseases. Unbelievably, the rate of STDs in the United States is the highest in the industrial

word, and it approximates the rates in the developing world in some populations. STDs cause infertility, cervical cancer, infant mortality. They are also fueling the HIV epidemic.

I have testimony which I will submit to you. I think it is all pretty shocking with regard to STDs and chlamydia in young people.

[The prepared statement of Congresswoman Connie Morella follows:]

[Pages 2273 - 2277--The official Committee record contains additional material here.]

Mrs. Morella. From 1988 to 1995, there was a drop of 65 percent in chlamydia positivity in the Pacific Northwest where the program was first implemented, and that is the Infertility Prevention Program administered by the Centers for Disease Control. We are asking it to be funded at \$60 million to reduce the severe and costly burden of STD-related infertility.

Also, we fully support the syphilis examination program at \$25 million. The highest incidence of syphilis is confined to specific regions, particularly in urban centers in the Southeast.

Osteoporosis, with continued funding we hope for research and public education.

Breast cancer, as has been mentioned, women continue to face a 1 in 8 chance of developing breast cancer during their lifetimes.

Of course, we are asking that you fund shelters for battered women and children at \$120 million and the National Domestic Women's Hotline at \$1.2 million in fiscal year 1999.

I very much appreciate, along with my colleagues in the Women's Caucus, the opportunity--every year we look forward to presenting to you many things that this committee already knows, but it is nice to know that we continue to push for it and you continue to follow through.

You have a good subcommittee, and you are great at the helm, thank you.

Mr. Porter. Thank you, Congresswoman Connie Morella and all those who testified. We will do our very best to respond to your priorities.

Thank you all very much. The subcommittee will recess until 2 next Wednesday.

Mrs. Morella. Can we make my full statement a part of the record?

Mr. Porter. Yes.

[Additional testimonies were prepared to be submitted for the record:]

[Pages 2279 - 2898--The official Committee record contains additional material here.]

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